FAMILY CENTERED ROUNDS: UNDERSTANDING DAILY PRACTICE AND IMPACT ON FAMILY EXPERIENCE

by

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Abstract

Background: Family Centered Rounds (FCR) are multidisciplinary rounds that are intended to engage patients and families in exchange of information and shared decision-making about a patient's care. The concept of FCR emerged in 2003, and it was introduced at a children's center within an academic medical center in 2008, though practice has been reported to vary across medical services and providers. Parents' and/or patients' experiences with FCR contribute to their overall hospital experiences. This study seeks to 1) understand and define the practice of FCR, and 2) understand the impact of FCR on parents' experiences while their children are hospitalized.

Methods: This dissertation begins with a synthesis of evidence gleaned from a scoping literature review of FCR with publication dates prior to February 2017. The evidence focuses on structure, process, and outcomes of FCR with an emphasis on family engagement in FCR. The remaining chapters describe a study that includes observations of 304 patient encounters during daily FCR on three medical teams on general medical/surgical units, as well as 28 semi-structured interviews with 31 parents to obtain parents' perspectives about their experiences with FCR.

Results: Results from these studies provide evidence of the benefits of FCR for patients, families, and providers. Results include descriptive statistics as well as qualitative observations of FCR as well as activities or tasks conducted during FCR. Nurses are among the providers who are most valuable to FCR. Some activities during FCR were shown to be performed more frequently than others, thus demonstrating inconsistencies in performance. Interviews with parents revealed their overall satisfaction with FCR and the opportunities for enhanced communication and information-sharing between all providers and better coordination of care. Parents also highlighted their concerns and aspects of FCR that could be improved in this hospital setting.

Conclusions: These studies demonstrate that FCR provide many benefits to parents as well as to providers, namely communication and exchange of information. Parents are generally satisfied with FCR and believe that FCR support participation as well as dignity and respect for parents' values and needs.

Parents' experiences with FCR could be improved for various reasons including better orientation to FCR and more consistent provider behavior during FCR.

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Chapter 1

THESIS OVERVIEW

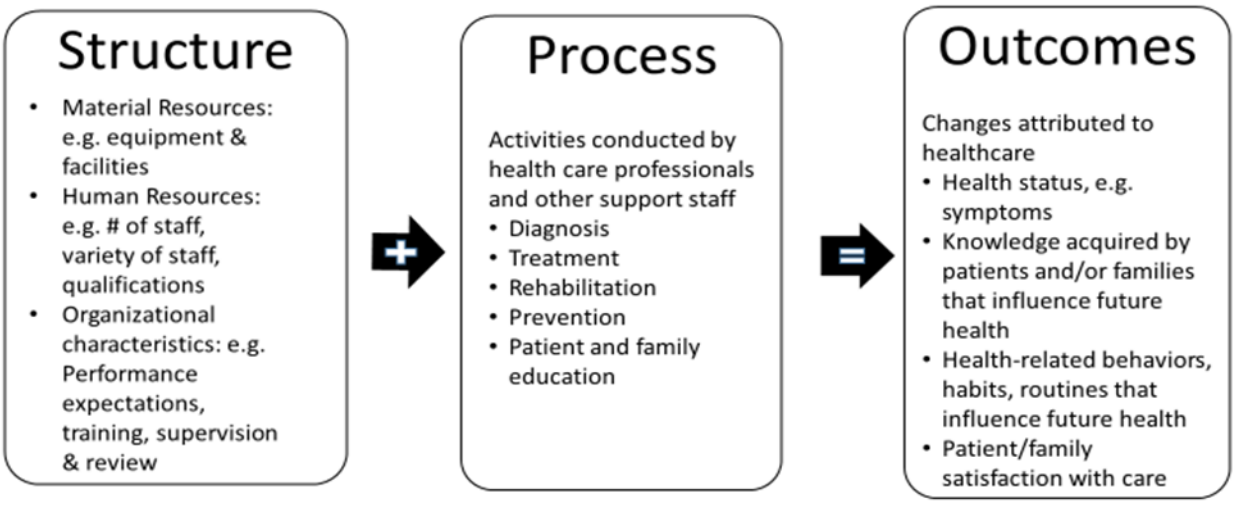
Patient- and family-centered care is a concept that was introduced in 1987 by the Surgeon General of the United States, C. Everett Koop. Koop (1987) advocated for collaboration between parents and professionals, sharing of information with parents, and respect for families and their care of their children; he urged systematic implementation of family-centered care across the continuum of inpatient and community-based or home-based care in order to achieve optimal outcomes that respected patients' and families' needs and values. Patient- and family-centered care may be defined and implemented in various ways in different settings. One strategy that could increase patient- and family-centered care and communication with families during hospitalization is family centered rounds (FCR). Family centered rounds ideally include the patient and family member at the bedside during interdisciplinary rounds to discuss and make decisions about the patient's care.

More recently, leadership in patient- and family-centered care was identified as one of six strategic priorities at a large academic medical center. The practice of Family Centered Rounds (FCR) is one component of patient- and family-centered care. FCR were implemented in the children's hospital associated with this academic medical center, beginning in July 2008, on general inpatient services and gradually expanded to include specialty services including cardiology, pulmonary medicine, hematology, the Pediatric Intensive Care Unit (PICU), and the Neonatal Intensive Care Unit (NICU). However, FCR are not practiced on all pediatric services, and anecdotal reports indicate that practice is inconsistent across services.

Several systematic models support the need to study and understand processes to achieve high quality outcomes. The Baldrige Performance Excellence Program provides a model that integrates systematic factors that contribute to performance excellence, including customer focus, operations, and

measurement/analysis to achieve excellence in outcomes or results (National Institute of Standards and Technology [NIST], 2015). Donabedian's model of quality of healthcare embodies three factors of structure, process, and outcomes (Donabedian, 2003). Both models emphasize processes or operations and patient or customer outcomes. For purposes of this research, Donabedian's model was applied to the study of family centered rounds. As seen in figure 1.1, Donabedian's model refers to *structure* as characteristics of an organization and includes physical facilities and equipment; human resources such as qualifications of health care providers, variety of providers, training or preparation of providers; and policies and performance expectations, e.g. providing residency training, and workload demands such as caseload size. *Process* refers to actions or behaviors that employees utilize; such actions are related to various aspects of care including diagnosis, treatment and intervention, rehabilitation, discharge planning, and education of patients and families. *Outcomes* refer to changes in the patient's health status and health-related behaviors, changes in patient and family knowledge, changes in patient and family satisfaction, and administrative or objective outcomes such as length of stay and cost.

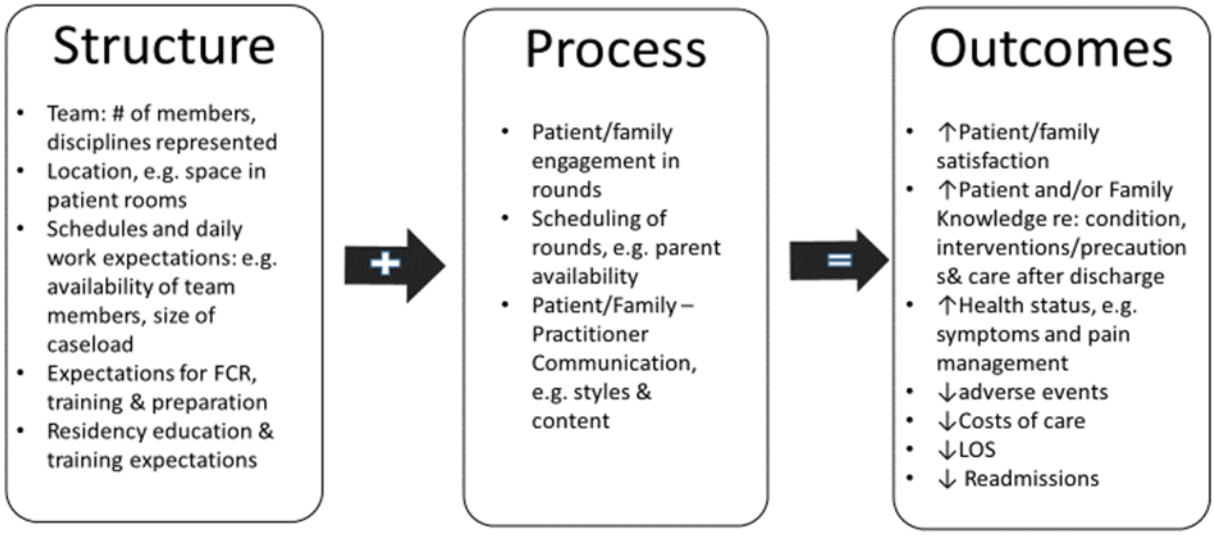
Figure 1.1. Donabedian's Model of Quality of Care



Donabedian, A. (2003). Selecting approaches to assessing performance. In Donabedian, A. *An Introduction to Quality Assurance in Health Care* (pp. 45-57). Oxford University Press, New York: New York.

When Donabedian's model is applied to FCR (figure 1.2), structure encompasses multiple factors such as the composition of the healthcare team, space, location for conducting FCR, caseloads, and residency training expectations. The process of FCR may include the scheduling of rounds because the schedule affects availability of families and staff, introduction of team members, presentations by healthcare providers, family engagement and participation in FCR, and other communication that occurs between families and health care providers. Outcomes may include subjective perceptions of patient and family satisfaction, improvement in health status and reduction in symptoms, changes in patient and family education, discharge readiness, and other objective measures such as length of stay, or decrease in adverse events. Patient- and family centered care, and specifically FCR, apply these principles in an effort to achieve high quality of the overall health care experience for the patient and family.

Figure 1.2. Donabedian's Model of Quality - Applied to Family Centered Rounds



Donabedian, A. (2003). Selecting approaches to assessing performance. In Donabedian, A. *An Introduction to Quality Assurance in Health Care* (pp. 45-57). Oxford University Press, New York: New York.

Using Donabedian's model as a framework, this thesis studied the structural and process elements of FCR to more clearly define the practice of FCR, concepts that are not wholly discussed in the literature. The study also analyzed parent feedback as an outcome to understand the family experience

with FCR. The results helped to identify best practice or quality of FCR while identifying possible strategies to enhance the practice of FCR in this setting and contribute to a higher quality family experience. Results of the research are presented in three manuscripts.

Manuscript I entails a scoping review of published evidence regarding FCR. This literature review considered structure, process, and outcomes of FCR with an emphasis on family engagement in FCR. The literature demonstrated that various structural elements affected the practice of FCR, that families and most healthcare providers appreciated families' input and participation, effective communication strategies are essential, and FCR are associated with higher satisfaction with care.

The second manuscript contains results from an observational study of FCR at the children's center at a large academic, tertiary hospital. This study includes descriptive statistics as well as qualitative descriptions that focus on structure and process elements of FCR as observed during the study. Results include descriptions of team sizes, caseloads, and frequency of participation in FCR by healthcare providers, families, and patients. Additional results describe healthcare provider behaviors during FCR related to dignity and respect, communication with parents, and communication between healthcare providers. This work helped to identify behaviors and contextual factors that comprise FCR while identifying inconsistent behaviors or aspects of FCR that may warrant further exploration and improvement.

Manuscript three presents the perspectives of parents who participated in FCR while their children were hospitalized; information was solicited through semi-structured interviews. This qualitative study includes themes related to parents' experiences with FCR and valuable aspects of FCR for parents including communication and exchange of information. In addition, parents noted various strategies to improve the process of FCR and thus enhance the hospital experience for parents while their children are hospitalized.

In summary, these three manuscripts contribute to the understanding of FCR, how FCR are practiced in a children's hospital, and the impact on the family experience. Such findings may contribute to further development and implementation of strategies to improve the quality of care and the patient/family experience through more effective FCR.

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Chapter 2

FAMILY CENTERED ROUNDS: A SCOPING REVIEW OF THE LITERATURE

Introduction

Patient- and family-centered care is a broad concept with various definitions and strategies of implementation. The Institute for Patient and Family Centered Care (IPFCC) embraces four key concepts of patient- and family-centered care: *respect and dignity*, *information sharing*, *participation*, and *collaboration* (IPFCC, n.d.). The goals of patient- and family-centered care are, broadly, to engage families in a collaborative relationship with healthcare professionals in order to provide the best quality of care, improve outcomes, lower costs, and increase patient satisfaction with health services. The American Academy of Pediatrics (AAP) recognized the importance of partnering with families to achieve optimal development and healthier outcomes (AAP, 2003). The importance of family-centered care is also noted by Healthy People 2020's objective of family-centered, comprehensive and coordinated systems of care for children with special health care needs (Healthy People 2020). Collaboration with parents or families allows a reciprocal sharing of information about the child's needs and preferences, medical care options, and recommendations. Parents and families are typically the primary caregivers for children, thus involving them in their child's care is essential (Mittal, 2014). Uhl, Fisher, Docherty, & Brandon (2013) identified parents' desires to be empowered with information about their child and the plan of care, and preparing effectively for discharge or transition. Engaging parents or families in care makes sense on a philosophical level in order to achieve better quality of care and to maintain continuity of care.

Background

In 2003, the American Academy of Pediatrics Committee on Hospital Care specifically recommended a new routine practice of inclusion of patients and families in bedside rounds for the purpose of dialogue and exchange of information, while integrating family input into decisions (AAP Committee on Hospital Care, 2003). Since then, family centered rounds (FCR) have become

commonplace in inpatient settings as a strategy that can support and increase patient- and family-centered care and communication with families. The practice continues to be supported by the AAP (2012). Family centered rounds are described as multidisciplinary rounds at the patient's bedside that include the patient and family in discussion about the patient's care and in decision-making (Mittal, 2014; Sisterhen, Blazsak, Woods & Smith, 2007). Professional team members may include attending physicians, residents, nurses, pharmacists, and other health care professionals who are caring for the patient.

Components of rounds ideally include asking the patient and/or family regarding their preference for participation, introductions of team members, description of the purpose of FCR, summary of the case with relevant test results, discussion of the daily plan and discharge goals with collaborative decisions (Muething, Kotagal, Schoettker, Gonzalez del Rey, & DeWitt 2007). Muething et al. (2007) and Sisterhen et al. (2007) further suggested that FCR provide opportunities for efficient communication via the presence of nurses and other healthcare providers who exchange relevant patient information; such enhanced communication may then facilitate more efficient coordination of discharge planning (Sisterhen et al., 2007). In addition, FCR provide opportunities for role modeling of effective communication behaviors and interactions with family members and other staff members as well as teaching trainees and families in the presence of real-time patient issues (Muething et al., 2007). Nichols, Crow, & Balakas (2015) described a process that included collaborative scheduling and role assignment to facilitate workflow and communication with nursing and trainees. Thus, FCR may provide opportunities for more efficient task completion in addition to facilitating more frequent and improved communication with families.

Patient- and family-centered care requires methods for operationalizing its concepts while assessing outcomes to demonstrate efficacy of this philosophical approach to care. Outcomes may support organizational strategies to more effectively implement patient- and family- centered care and

overcome barriers. Systematic models provide frameworks for studying healthcare practices and associated outcomes. One such model, Donabedian's model of quality of care, embodies three factors of structure, process, and outcomes (Donabedian, 2003). When applied to FCR, *structure* encompasses multiple factors such as size and composition of the healthcare team, administrative expectations and workload demands, space, and location for conducting FCR. *Process* refers to actions or behaviors during FCR such as scheduling and availability of families, the frequency and quality of family engagement in FCR discussions, and the communication that occurs between families and healthcare providers. *Outcomes* may include subjective reports of patient and/or family satisfaction or experience, improvement in health status, changes in patient/family education, discharge readiness, and other administrative outcomes measures such as length of stay or costs.

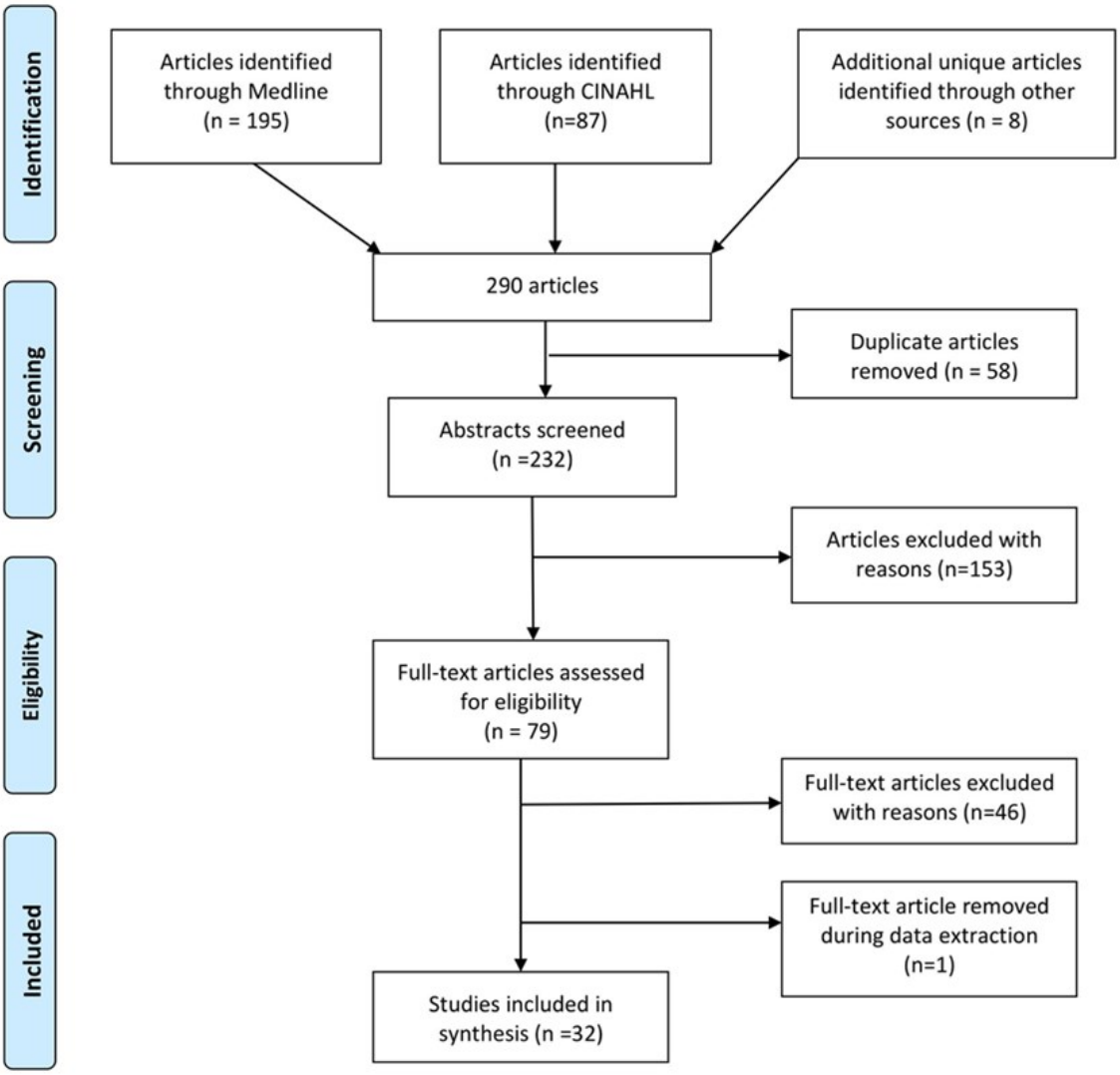
Using Donabedian's framework, the following literature review is intended to explore and summarize the evidence on FCR in order to more fully understand the structure, process, and outcomes of FCR, especially as related to patient and/or family participation and experience. The results may contribute to a better understanding of effective elements and strategies to operationalize family centered rounds while summarizing outcomes of rounds related to family participation and experience.

Methods

A literature search was conducted with Medline and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) to identify peer-reviewed articles published in English prior to February 2017. Search terms included: *family centered rounds, family centred rounds, bedside rounds* and *families, patient centered rounds, patient centred rounds* and *families, hospital rounds* and *pediatrics, interdisciplinary rounds* and *pediatrics,* and *family rounds* and *pediatrics.* During the initial search process, articles whose titles clearly did not address rounds were excluded (i.e. some article titles reflected use of specific medical interventions and not rounds). The Medline search returned 195 possible articles, and CINAHL returned 87 possible articles. Eight additional eligible articles were

identified by manually reviewing the reference lists of articles gleaned from the initial database searches; these additional articles addressed family centered rounds and were unique from the previously identified CINAHL and Medline searches. Full text of included articles was available online or via interlibrary loan. Fifty-eight duplicate articles were removed from the initial search results. Figure 2.1 describes the process for inclusion and exclusion of articles.

Figure 2.1: Scoping Review: Selection of Articles Regarding Family Centered Rounds



From: From Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Abstracts of 232 articles were then screened for further decisions regarding inclusion in the analysis. Articles were included if they addressed pediatric inpatient hospital settings and addressed daily rounds for patients with parent/family participation. Exclusion criteria and the number of excluded articles during the screening phase are listed in Table 2.1. The remaining 79 articles were further reviewed for inclusion if they met the overall study objectives. Inclusion criteria included studies with empirical data and that addressed patient and/or family engagement in daily rounds. The primary researcher (DWB) reviewed the articles, and a secondary researcher (PD) consulted on the review. They discussed the articles and came to consensus on excluding 46 articles as described in table 2.2. The quality of research methodologies was also reviewed during this phase, and four studies with weak methodologies were excluded.

Table 2.1. Articles excluded from initial screening (n=153)

Rationale	n
Rounds not Family-centered	67
Adult Populations	50
Editorials/Commentaries	18
Brief Reports/Abstracts or no empirical data	15
Prior Literature Reviews/Secondary data	2
Humor/Facetious	1

Thirty-three articles were thus deemed eligible for final analysis. Data was extracted from these 33 studies by the primary researcher (DWB) as well as a second reader (SM). The primary and secondary reader independently read and reviewed the literature and independently abstracted study characteristics including type of study, study design, sample size, methods utilized, key findings or results, and strengths/limitations of the studies. During this phase of data extraction, one additional article was removed because its results compared pediatric rounds to adult rounds and did not fully address the practice of pediatric family centered rounds. Results from the remaining 32 studies were synthesized and summarized to identify common themes; elements of structure, process, and outcomes of FCR; and

Table 2.2. Articles excluded from final review (n=46)

Rationale	n
Primarily Education/training	13
Conceptual and/or no empirical evidence	8
Did not address family engagement or FCR	11
QI projects with insufficient data analysis	7
Insufficient rigor of studies	4
Pediatric results indistinct from adults	2
Systematic review with secondary data	1

implications for the practice of FCR. Researchers (DWB and SM) reviewed their analyses to determine consensus or congruity on the characteristics and conclusions of the studies and the overarching conclusions. Congruity of agreement between two readers strengthens the reliability of the findings and conclusions (Cooper, 2010). Quantitative meta-analysis was not conducted due to the use of various non-standardized, quantitative, site-specific measurement tools across studies.

RESULTS

Articles are displayed in table 2.3.

Table 2.3. Data Extraction from Final Articles in Review

Author, Year, and Country	Study Design & Setting	Instruments	Participants and sample size	Significant Results	Study Limitations
Abdel-Latif, M. E., Boswell, D., Broom, M., Smith, J., & Davis, D. (2015).	Randomized Cross-over NICU[a]	• Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU) • Focus group • Satisfaction scale	Parents (n=63) Parents - Focus group (n=9) Health care providers (n=39)	• 95% parents & 90% providers believed parents should participate in rounds. • Parents reported significantly higher satisfaction with bedside rounds re: understanding, communication and collaboration. • No difference in PSS: NICU between bedside vs. non-bedside rounds. • Parents & providers reported superior communication in bedside rounds. • Parents preferred to hear information directly from senior physicians. • Providers perceived negative impact on education & team discussions in bedside rounds. • Parents saw themselves as a "constant" in child's life across providers.	• Single site • Limited to NICU • Site-specific satisfaction scale • Small sample size for focus groups • Majority of provider participants were nurses with limited input from physicians • Excluded non-English speaking parents
Aronson, P. L., Yau, J., Helfaer, M. A., & Morrison, W. (2009).	Prospective Observational study PICU[b]	• Observation checklist • Family Survey • Resident Survey	Patient Encounters on Rounds (n=411) Family (n=98) Residents (n=33)	• 98% of families and 85% of residents believed families should participate in rounds. Families participated in 52% of rounds. • Team introductions occurred in 11% of rounds. • No significant difference for rounding time with family presence, after adjustment for contextual factors. • Subspecialist participation was associated with increased rounding time.	• Single site • Limited to PICU • Site-specific questionnaires & checklist • No control group • Did not observe weekend rounds

				• 52% of residents reported that teaching was decreased with family presence. • Families had more concerns and needed additional support on day of admission. • >90% of families felt confident with residents & team and reported it is helpful to hear about their child's case.	
Balmer, D. F., Master, C. L., Richards, B. F., Serwint, J. R., & Giardino, A. P. (2010).	Qualitative and observational General Pediatric hospital unit	• Observation • Semi-structured Interviews	Patient encounters on rounds (n=205) Residents & attending physicians (n=39)	• 81% of rounds occurred in hallway outside patient rooms with 17% at the bedside and 2% in conference rooms. • Parents participated in 25% of rounds. • Teaching was valued and expected during rounds. • Residents and attending physicians reported tension between teaching and clinical demands, especially time-constraints. • Parent presence on rounds was viewed as a possible barrier to teaching and as an extra time-constraint.	• Single site • Limited to general pediatrics – no specialty services • Site-specific observation tool or questionnaire; no discussion of development of questions • Did not report inclusion or exclusion criteria for interviews
Beck, J., Meyer, R., Kind, T., & Bhansali, P. (2015).	Qualitative General and specialty units	Focus groups	Nurses (n=15) Family members (n=13)	Attending physicians need situational awareness and should adjust rounds as needed for these factors: • Cognitive: family knowledge & experience, trainees' needs • Logistics/Time: team size & introductions, family orientation to FCR, nurse and family input, relevant discussions during rounds • Physical environment: patient room and how families are engaged • Emotional State: patient & family comfort, trainees' anxiety	• Single site • Small sample size • Purposive sampling

Benjamin, J. M., Cox, E. D., Trapskin, P. J., Rajamanickam, V. P., Jorgenson, R. C., Weber, H. L., … Lubcke, N. L. (2015).	Qualitative Observational General pediatrics, pulmonary, hematology/ oncology	Video recordings of FCR for coding	Video-recordings of FCR (n=347)	• 55% of families initiated discussion of medications. • 65% of questions addressed inpatient medications; 35% addressed home medications. • Medication schedules were the most frequent topic (24%); adverse drug reactions were the second most frequent topics (11%). • 74% of families' questions were directly answered during rounds. • 8% of family-initiated discussions resulted in medication changes.	• Single site • Higher proportion of video recordings in general hospital services
Berkwitt, A., & Grossman, M. (2015).	Qualitative, descriptive General pediatric	Semi-structured interviews	Children ages 7-18 years (n=22)	• Patients had mixed opinions re: team size, content of discussion in rounds. • Patients preferred orientation to rounds, team introductions, inclusion in discussion, explanations and information, and knowing the daily plan. • Patients' negative perceptions included new or unfamiliar information, being "on display", invasion of personal space, and feeling anxious during rounds. • Schedule of rounds was too early and disrupted sleep.	• Single site • Limited to general pediatrics - no specialty services • Small sample size • Practice of FCR differed across providers • Excluded non-English speaking patients • No discussion of development and validation of interview questions
Bhansali, P., Birch, S., Campbell, J. K., Agrawal, D., Hoffner, W.,	Prospective Observational	Observations	Patient encounters on rounds (n=159)	• Average time per patient = 7.9 minutes • Longer duration of rounds was associated with multiple trainees performing exams. • Location of rounds did not affect time.	• Single site • Did not observe weekends

Manicone, P., … Ottolini, M. (2013).	General pediatrics & neurology			• 54% of FCR occurred outside patients' rooms. • Infectious isolation precautions were associated with FCR outside of rooms. • Neurology rounds were more likely to occur outside of patient rooms. • Parents were present for 72% of rounds. • Nurses were present for 69% of FCR.	
Cameron, M. A., Schleien, C. L., & Morris, M. C. (2009).	Prospective Observational PICU	• Observation • Semi-structured interviews • Brief & written surveys	Patient encounters on rounds (n=130) Parent interviews (n=52) Health Care providers' brief surveys (n=375) Written surveys from Nurses (n=63) and physicians (n=39)	• Parents participated in 37% of rounds. • Physician providers perceived that parent presence increased time for rounds and limited teaching in rounds. • No statistical difference in time of rounds with family presence. • Health care providers and parents agreed that parent presence enhanced information exchange. • 57% of Providers reported learning new information from parents. • 32% providers reported that parent presence limited discussion. • 75% of parents felt rounds provided opportunities to participate in decisions, and 89% reported improved understanding of treatment plan. • 83% of parents were satisfied with FCR.	• Single site • Limited to PICU • Excluded non-English speaking parents • No assessment of actual teaching despite concerns of FCR limiting teaching noted by providers
Carayon, P., Li, Y., Kelly, M. M., DuBenske, L. L., Xie, A., McCabe, B., … Cox, E. D. (2014).	Qualitative General pediatrics, pulmonary and hematology/ oncology	Stimulated recall through videos, with interviews	Parents (n=5) Physicians (n=4) Nurse (n=1)	1) Providers indicated they would change behaviors after viewing videos of FCR. 2) Facilitators and barriers to FCR were identified across Human Factors & Ergonomics: • Person, e.g. provider interaction, parent preferences & knowledge • Environment, e.g. location, interruptions	• Single site • Small sample size

				• Tools/technology, e.g. computer use • Organizational, e.g. scheduling, nurse presence, team size • Tasks, e.g. communication & terminology, nurse workloads	
Chand, D. V. (2011).	Prospective pre- and post-design General pediatrics	• Observation • Survey	Residents (n=37) Attending Physicians (n=7) Nurses (n=54) Parents (n=48)	After Lean Six Sigma approaches were applied: • Pre-rounding time was eliminated. • Work tasks for bedside rounds were standardized and more efficient, e.g. one collaborative note with team. • Median rounding time decreased per patient by 50%. • Non-value-added time by residents was reduced by 64%, e.g. less waiting time. • Providers preferred the improved process and perceived it to be more efficient.	• Single site • Limited to general pediatrics – no specialty services • Site specific surveys • Unequal sample size between pre- and post- surveys
Drago, M. J., Aronson, P. L., Madrigal, V., Yau, J., & Morrison, W. (2013).	Mixed Methods PICU	• Observation • Survey	Patient encounters on rounds (n=431) Family members (n-100)	• Mothers were the most frequent family member in rounds. • Regardless of family presence on rounds, family members believed family presence improved quality of care. • Family preference for participation was the only characteristic associated with higher attendance at FCR. • Family presence was associated with higher rate of FCR at the bedside vs. hallway.	• Single site • Limited to PICU • Site specific survey • Undefined method of documenting observations • Excluded non-English speaking families • Did not observe weekends
Kelly, M. M., Xie, A., Carayon, P.,	Qualitative	Stimulated recall with interviews	Parents (n=11) Children (n=4)	Identified various strategies to improve family participation in FCR: • People: Team size	• Single site • Small sample size, esp. children

DuBenske, L. L., Ehlenbach, M. L., & Cox, E. D. (2013).	General pediatrics, pulmonary, hematology/ oncology		Healthcare Providers (n=22)	• Tasks: Role definition • Organization: Scheduling, training re: FCR • Environment: Location, physical space • Tools/Technology: Computer use Additional strategies were identified as orienting families to FCR, introducing team members, using lay language, minimizing interruptions, and providing time for nursing input.	• Excluded non-English speaking parents/patients
Kuo, D. Z., Sisterhen, L. L., Sigrest, T. E., Biazo, J. M., Aitken, M. E., & Smith, C. E. (2012).	Mixed methods, prospective cohort General pediatrics	• HCAHPS®[c] • Interview	Parents who participated in FCR (n=49) Parents who did not participate in FCR (n=48)	Families in FCR reported: • Higher satisfaction, more consistent medical information and options to discuss care plans; higher participation in FCR and more FCR at the bedside. • Doctors listen carefully and show respect. No differences were found in • Feeling like a partner in care, knowing doctors' names, doctors explaining things carefully or understanding discharge plans. • Hospital charges after adjusting for LOS/ • Discharge time of day. • Number of medications ordered.	• Single site • Limited to general pediatrics - no specialty services • HCAHPS® was the adult version • Did not observe rounds to verify consistent practice of FCR
Ladak, L. A., Premji, S. S., Amanullah, M. M., Haque, A., Ajani, K., & Siddiqui, F. J. (2013).	Mixed methods, incl. pre- and post-design PICU and pediatric cardiac ICU	• Observation • Survey	Parents (n=82, evenly pre – and post- samples) Healthcare providers (n=25)	• Parents preferred FCR and were more satisfied with Inclusion in discussion & decision-making, use of simple language during rounds, and evidence of teamwork. • No difference was found in providers' satisfaction between FCR and traditional rounds.	• Single site, private hospital • Very small ICU (5 beds total)

				• No significant difference was noted in duration of rounds between FCR vs. traditional rounds. • Median LOS was significantly shorter for patients who had FCR. • FCR provided opportunities for parents to correct errors or add missing information in documentation and medical history.	
Landry M, Lafrenaye S, Roy M, & Cyr C. (2007).	Randomized Control PICU	Survey	Parents (n=27) Residents (n=21)	• Parents preferred bedside presentations and reported higher overall satisfaction with bedside case presentations. • Parents were more satisfied with elements of privacy and intimacy, and were more informed about tests during bedside rounds. • Residents' overall satisfaction did not differ between conference room vs. bedside presentations. • Residents felt more comfortable asking questions in conference room rounds. • Residents believed bedside presentations are beneficial for parents but also believed this may be more distressing to families and patients.	• Single site • Limited to PICU that excluded cardiac or transplant surgery • Site-specific survey • Small sample size
Latta, L. C., Dick, R., Parry, C., & Tamura, G. S. (2008).	Qualitative, descriptive General pediatrics	Semi-structured interviews	Parents (n=18)	• All participants were satisfied with FCR. Three primary themes: • Communication improved information exchange. Child's diagnosis was the most common goal for information. Nurse participation in rounds was also valued to help parents obtain and understand information.	• Single site • Limited to general pediatrics - no specialty services • Site-specific survey • Small sample size

				• Participation in FCR provided opportunities to be part of the team, and parents perceived more comfort, encouragement, respect and listening. • Teamwork was enhanced during FCR.		
Levin, A. B., Fisher, K. R., Cato, K. D., Zurca, A. D., & October, T. W. (2015).	Prospective, cross-sectional mixed methods PICU	• Observation • Surveys	Patient Encounters on rounds (n=232) Family Members (n=92) Nurses (n=64) Physicians (n=271)	• 85% of providers believed families should be invited to FCR, and 52% of FCR included family presence. • >50% of physicians believed family presence lengthened rounding time, and >50% of nurses thought family presence limited discussion. • Longer duration of rounds was associated with family talking time, however, average family talk time was 25 seconds or 4% of rounding time, suggesting that providers' behavior may differ with family presence during FCR. • Information for families was the most frequent benefit of family presence according to family members and health care providers. • >50% of health care providers believed families contributed valuable information. • Non-English-speaking families had lower rates of attendance in FCR. • >50% of families suggested that being "considerate" would improve FCR.	• Single site • Limited to PICU, which does not include cardiac surgery • Limited response rate from families who did not participate in FCR
Lewis, C., Knopf, D., Chastain-Lorber, K., Ablin, A.,	Mixed methods, pre- and post-design	• Interviews • Surveys	Parents (n=40) Patients (n=22) Residents (n=9)	• 82% of parents preferred bedside rounds. • Parents and residents agreed that bedside rounds provided opportunities for parents to receive information.	• Single site • Limited to oncology • Small sample size	

Zoger, S., Matthay, K., … Pantell, R. (1988).	Oncology			• Parents reported that bedside rounds were less confusing and allowed them to ask questions. • Parents and children had different opinions about possible emotional upset during bedside rounds. • Children's suggestions to improve bedside rounds were to decrease team size and use more simple language. • Residents preferred standard rounds for their education, but agreed that bedside rounds were beneficial for them to develop physical examination skills and communication or rapport with families. • Children without bedside rounds were less likely to hear good news.	
Lion, K. C., Mangione-Smith, R., Martyn, M., Hencz, P., Fernandez, J., & Tamura, G. (2013).	Mixed methods, prospective cohort General pediatrics	• Observation • Interviews	English-proficient (EP) Parents (n=41) Limited English Proficiency (LEP) Parents (n=40)	• Providers were more likely to use lay language with LEP parents. • Providers were more likely to discuss initial medical issues without LEP parents. • 50% of LEP families experienced information "filtering" by interpreters which led to lower odds of knowing child's diagnosis. • LEP parents with prior admission were more likely to understand child's diagnosis. • EP and LEP parents had no significant difference in knowing child's diagnosis and care plan.	• Single site • Limited to general pediatrics -no specialty services • Telephone interpreters were used vs. in-person • LEP families were predominantly Spanish-speaking with small proportions of other languages
Mittal, V. S., Sigrest, T., Ottolini, M. C.,	Cross sectional	Pediatric Research in Inpatient Setting	Hospitalist physicians (n=265)	• 44% of rounds were FCR and more often occurred in academic hospitals.	• Individual responses may over-represent

Rauch, D., Lin, H., Kit, B., … Flores, G. (2010).	80 hospitals with broad representation of general pediatrics and specialty services	(PRIS) Network triennial survey		• Team size: 61% of teams are 6-10 people; 13% of teams >10 people • Nurse presence was higher during FCR. • FCR were not associated with longer rounds. Longer rounds were associated with higher census and academic settings. • >50% of physicians believed FCR increased patient & family engagement, educational role modeling, patient & family understanding of discharge goals, team communication, discharge workflow, and time efficiency. • Barriers to FCR were: large team size, trainees' fear of insufficient knowledge in front of families. • Physicians who did not use FCR were more likely to report barriers as privacy/confidentiality and negative workflow.	some organizations based on distribution of respondents • Limited to PRIS members • Missing data from some survey questions • Did not address potential language barriers
Oshimura, J. M., Downs, S. M., & Saysana, M. (2014).	Retrospective pre- and post-design General pediatrics	Chart Review	pediatric admissions (n=1823 with 912 pre-FCR and 911 post-FCR)	After FCR were implemented: • a higher proportion of discharges occurred before 3:00 PM. • the time to complete EEGs and MRIs decreased.	• Single site • Limited to general pediatrics - no specialty services • Did not assess changes in patient morbidity or readmissions • Did not analyze subgroup of patients who did not receive MRI/EEG

Phipps, L. M., Bartke, C. N., Spear, D. A., Jones, L. F., Foerster, C. P., Killian, M. E., … Thomas, N. J. (2007).	Prospective Observational, Mixed Methods PICU	• Observation • Survey	Patient Encounters on Rounds (n=105) Family members (n=81) Health Care Providers (n=187)	• Median team size = 7 people • Family members were present for 60% of FCR. • Family presence had no effect on length of FCR or on teaching time. • 95% of families reported they understood the treatment plan, but medical terminology was the most common reason for inability to understand plans. • 95% of health care providers believed family presence did not interfere with discussion. • 67% of families were able to ask questions during FCR.	• Single site • Limited to PICU • No control group • Observation form and survey were not defined or described • Excluded non-English speaking families or children with chronic ventilatory dependence
Pickel, S., Shen, M. W., & Hovinga, C. (2016).	Mixed methods General pediatric services	• Observation • Surveys	Patient encounters on rounds (n=301) Physicians, residents & medical students (n=34)	• 78% of all rounds were FCR, located in patient rooms with family presence. • Average time in patients' rooms was 7 minutes with 6.4 minutes between rooms. • Attending physicians spoke more than other team members in rooms; family members had the second highest amount of speaking time in rooms. Nurses spoke the least amount of time in rooms. • Longer FCR was associated with >2 family members present in room or if patient was deemed to be complex. • Shorter rounds occurred with families who had limited English proficiency. Medical team members served as translators in 15% of FCR.	• Single site • Limited to general pediatrics – no specialty services • Site-specific observation form and survey • Responses are limited to medical team only, no other providers or family input.

				• Medical teams perceived longer duration of FCR and different proportions of speaking time for family members and patients. • Overall nurse presence was 44.7% on FCR, but presence increased significantly if nurses received prior notification.	
Rappaport, D. I., Ketterer, T. A., Nilforoshan, V., & Sharif, I. (2012).	Mixed methods General pediatrics	• Observation • Survey	Patient encounters on rounds (n=295) Family members (n=137) Health care providers (n=257)	• Average rounding time and transition time between patients was reduced with family and nurse presence. • Overall, family members' satisfaction with rounds was high. • Family presence in FCR was associated with family members' knowledge of team members' roles but not associated with any other satisfaction factors. • Health care providers were overall satisfied with family presence in FCR but had slight differences in specific factors. • Senior residents had higher concerns with autonomy in FCR with increased family participation. • Overall, nurses were more satisfied with higher family participation.	• Single site • Limited to general pediatrics – no specialty services • Site-specific observation tool and surveys • Observations excluded weekends, Mondays & Fridays
Seltz, L. B., Zimmer, L., Ochoa-Nunez, L., Rustici, M., Bryant, L., & Fox, D. (2011).	Qualitative, exploratory General pediatrics	Focus groups	Latino Family members Parents (n=27) Patient (n=1)	• Participants reported higher satisfaction during FCR with a Spanish-speaking health care provider. • Participants were dissatisfied with telephone interpreters and strongly preferred live interpreters. • Without interpretation or Spanish language, participants' comprehension was limited.	• Single site • Limited to general pediatrics – no specialty services • Latino families were all from Mexican backgrounds; may not generalize to

				• Participants felt embarrassed by language barriers and did not feel empowered to speak up. • Families valued the presence of nursing staff during FCR. • Families had varied opinions regarding the presence of extended family members during FCR. • Participants did not understand the purpose or process of FCR, and they preferred prior orientation.	other Latino populations • Some focus groups included extended family members which may have hindered parents' full disclosure • Inclusion of one patient does not fully represent patients' views
Stickney, C. A., Ziniel, S. I., Brett, M. S., & Troug, R. D. (2014a).	Cross sectional PICU	Survey	Parents (n=100) Health Care Providers (n=131)	• 92% of parents desired to attend FCR. • Health Care Providers expressed a range of responses but overall 54% preferred parent presence. • Feeling welcome was the only factor that predicted family attendance in FCR. • Parents and health care providers differed in their perceptions of parents' understanding of FCR. • 86% of physicians thought parent presence limited discussion; 75% of physicians perceived longer rounds with family presence; 66% of physicians were less comfortable with teaching in FCR. • 84% of parents and 73% of providers believed communication was improved with FCR. • 91% of nurses believed providers should provide a 1:1 follow up with families after rounds.	• Single site • Limited to PICU • Site-specific survey

Stickney, C. A., Ziniel, S. I., Brett, M. S., & Troug, R. D. (2014b).	Qualitative, exploratory PICU	• Focus groups • Semi-structured interviews	Health care providers (n=24) Parents (n=21)	• Providers and parents agreed that parents' presence in rounds improved parents' understanding of child's status and plan while increasing communication. • Parents' expectations included obtaining information with clear communication and opportunities to provide input as "experts" on their children. • Parents reported that rounds provided an opportunity to hear & see team collaboration, to understand team members' roles, and to feel included in their child's care. • Parents' concerns with rounds included the possibility for feeling intimidated, not understanding terminology, or hearing unexpected or negative news. • Parents expressed more comfort in rounds when they were invited, were addressed by team members, and were solicited for questions or input. • Parents valued the bedside nurse. • Parents typically were not oriented to rounds but most did not desire an explanation beforehand. In contrast, providers believed parents should receive orientation to rounds by the nurse at admission. • Providers typically viewed parent presence as contributing to longer rounds with limited attention to teaching.	• Single site • Limited to PICU • Site-specific surveys • Excluded parents who did not participate in rounds

				• Providers viewed parent presence as limiting discussion, coupled with a desire to avoid uncertainty in the presence of parents. This led to medical teams conducting pre- or post- rounds discussions that excluded nurses.		
Subramony, A., Schwartz, T., & Hametz, P. (2012).	Observational, cross sectional General Pediatrics	• Survey • Chart Review	Family Members' surveys matched with chart review (n=118)	• 82% of parents accurately identified discharge goals; 74% of parents accurately identified discharge medications, and 48% of parents accurately identified discharge day. • Non-Hispanic parents had higher rates of accurately identifying discharge day. • English-speaking parents were more likely to report knowing discharge goals and discharge medications, but accuracy with the medical charts did not differ between English-speaking and Spanish-speaking families.	• Single site • Limited to general pediatrics – no specialty services • Site-specific survey • Did not describe if interpreters were provided during rounds • Did not observe FCR to validate discharge discussion during FCR • No control group
Voos, K. C., Ross, G., Ward, M. J., Yohay, A.-L., Nena Osorio, S., & Perlman, J. M. (2011).	Pre- and post-design NICU	• Collaboration & Satisfaction about Care Decisions (CSACD) • Parent Stress Scale: Neonatal Intensive Care Unit (PSS: NICU)	Health Care Providers (n=278; 142 pre - & 136 post- FCR) Parents (n=28; 12 pre- and 16 post-FCR)	• Health care providers' CSACD scores were significantly higher post-FCR, but further analysis revealed higher scores only for fellows and nurse practitioners. • PSS:NICU displayed no difference in parent stress pre- and post- FCR. • NIPS displayed higher parent satisfaction on questions related to communication and being kept informed, but no difference occurred in the overall satisfaction scores.	• Single site • Limited to NICU • Small sample size of parents

		• Neonatal Instrument of Parent Satisfaction (NIPS)			
Walker-Vischer, L., Hill, C., & Mendez, S. S. (2015).	Qualitative, descriptive General pediatrics and PICU	Survey	Latino Parents who participated in FCR (n=17)	Four primary themes emerged: • Participation & Value: Parents' participation and input were valued. • Inclusion & Care: Parents felt included in FCR and believed child's care was better. Parents noted that nurse presence in FCR was important. • Facilitated Communication: FCR improved communication and contributed to better understanding. Explanations in Spanish, with interpreters if needed, were essential. • Meeting expectations: Families desired physicians to return after FCR for further explanation or to see patient more than once per day.	• Single site • Site-specific survey • Small sample size • Themes were not substantiated with direct quotes from survey responses
Whelihan, E. (2015).	Pre- and post-design NICU	• Collaboration & Satisfaction about Care Decisions (CSACD) • HCAHPS®	NICU Staff (n=13) Parents (n=96; 42 pre- and 54- post FCR)	• Overall CSACD scores declined post-FCR. However, higher satisfaction with decision-making was correlated with responses of higher collaboration. • HCAHPS® scores improved in questions regarding nurse communication, doctors keeping parents informed, and doctors involving parent in decisions.	• Single site • Limited to NICU • Small sample size • HCAHPS® was adult version • No statistical analysis of HCAHPS® scores
Xie, A., Carayon, P., Cox, E. D., Cartmill, R., Li, Y., Wetterneck,	Mixed methods General Pediatrics,	• Observation • Semi-structured interview • Survey	Observations of FCR (n=47) Various stakeholders –	• Development and pilot of FCR checklist • Facilitators of checklist use: team familiarity with checklist, pre-round huddles & de-briefing, clear team roles	• Single site • Researchers may have been biased with evaluation of the FCR checklist

T. B., & Kelly, M. M. (2015).	hematology/ oncology		parents, administrators, nurses, nurse managers, physicians, resident (n varied based on tasks and roles in the project)	• Barriers to checklist use: lack of mobile computer, higher census, demanding tasks, various specialists on team, early in rotation for senior residents, isolation precautions, interruptions during rounds • Teams had higher rates of discussing assessment and ensuring nurse presence. • Teams had lower rates of asking team for questions and reading back orders.	because they were also involved in its development.

Note. [a]NICU = Neonatal Intensive Care Unit.
[b]PICU = Pediatric Intensive Care Unit.
[c]HCAHPS® = Hospital Consumer Assessment of Healthcare Providers and Systems.

Study characteristics

Twenty-eight studies were conducted in the United States (US). Of the four remaining studies, three were in Canada, Australia, and jointly in Canada & the US, respectively. Only one study occurred in a non-western culture and low-income country of Pakistan (Ladek et al., 2013). Thirty-one of the articles were published between 2007-2016 with the highest concentration between 2013 and 2015. Almost all of the studies were conducted in single hospitals; only one (Mittal et al., 2010) included multiple sites. Eleven studies were conducted on general inpatient pediatric services, while eight studies covered a combination of general pediatric services and subspecialty services. Twelve studies focused solely on Pediatric or Neonatal Intensive Care Units (PICU, NICU). Only one study (Lewis et al., 1988) was performed solely with a subspecialty population. No studies addressed psychiatric or behavioral health services.

Although many studies directly observed FCR in pediatric settings, participants in the associated surveys and questionnaires were predominantly parents and/or health care professionals. Only three studies (Berkwitt & Grossman, 2015; Kelly, et al., 2013; Lewis et al., 1988) obtained direct responses or input from children or adolescents. Most of the studies excluded non-English speaking participants, although three studies (Lion et al., 2013; Seltz, et al., 2011; Walker-Vischer et al., 2015) specifically investigated FCR with non-English speaking families, and the study in Pakistan (Ladek et al., 2013) included participants who spoke a local language. Pickel et al. (2016), Rappaport et al. (2012), and Subramony et al. (2012) included Spanish-speaking families in their studies.

Study methodologies used various designs that reflected mostly qualitative or mixed methods designs. Overall, studies had limited use of standardized measurement tools, and many utilized their own site-specific questionnaires or surveys.

Structural Elements of FCR

Family centered rounds occurred in various locations including hallways and patient rooms; frequency of rounds in patients' rooms ranged from 17% (Balmer, et al., 2010) to 78% (Pickel, et al.,

2016). Parents preferred that rounds occur in their child's room (Beck et al., 2015; Landry et al., 2007; Lewis et al., 1988), and rounds were more likely to occur in patients' rooms when families were present (Drago et al., 2013). Parents reported feeling less anxious when rounds were conducted in the patients' rooms (Cameron et al., 2009; Ladek et al., 2013). Similarly, adolescents and children indicated that they felt somewhat less anxious when rounds were conducted in their rooms versus in the hallway outside their rooms (Berkwitt & Grossman, 2015). Rates of family and parent presence at rounds ranged from 25% (Balmer et al., 2010) to 78% (Pickel, Shen & Hovinga, 2016) of the time, among studies that reported this variable. None of the studies in this review reported the inclusion of weekend rounding practices in their research.

Team size was documented in two studies; Phipps et al. (2007) reported a median team size of seven members, while Mittal et al. (2010) reported a range of 6-10 members in more than 60% of settings with only 13% of teams being larger than ten members. Several studies indicated that larger team sizes inhibited the rounds process for families (Beck et al., 2015; Carayon et al., 2014; Xie et al., 2015) and health care providers (Mittal et al., 2010) for various reasons including physical space limitations. Team composition was often described by listing participating health care disciplines. Specifically, the medical teams typically included an attending physician or hospitalist, several residents, interns and medical students. Inclusion of other health care team members varied by study but included nurses, nurse practitioners, pharmacists, respiratory therapists, or other providers based on the context of each setting. Nursing staff presence emerged in multiple studies as a valuable component of FCR for both families as well as for other health care providers (Carayon et al., 2014; Latta et al., 2008; Seltz et al., 2011; Walker-Vischer et al., 2015).

Process Elements of FCR

Overwhelmingly, parents and health care providers were in favor of parents' or families' participation in FCR. Families with limited English-proficiency were less likely to attend rounds (Levin et

al., 2015) or were excluded from some medical discussions (Lion et al., 2013). Various studies noted suggestions or recommendations by families to improve the process of FCR such as listening, acknowledging parents' experience and knowledge, making eye contact, limiting distractions during rounds, using lay language, and showing respect (Beck et al., 2015; Kelly et al., 2013; Ladek et al., 2013; Stickney et al, 2014b). Beck et al. (2015) also suggested that teams should assess patients' and families' emotional state and adjust rounds if needed, i.e. avoid discussing sensitive topics in patients' presence. Parents (Levin et al., 2015; Seltz et al., 2011) and pediatric patients (Berkwitt & Grossman, 2015) reported that they would prefer to receive some sort of prior orientation to FCR to be better prepared for rounds.

Communication was viewed by both parents and health care providers in multiple studies as a positive component of FCR (Abdel-Latif et al., 2015; Stickney et al., 2014a; Walker-Vischer et al., 2015). More specifically, the exchange of information was cited as the most or one of the most valuable aspects of FCR (Cameron et al., 2009; Latta et al., 2008). Parents believed they had input into decisions about care (Cameron et al., 2009; Kuo et al., 2012; Ladak et al., 2013). Several studies reported that parents preferred the use of lay language versus medical terminology as being more helpful (Latta et al., 2008; Lewis et al., 1988; Phipps et al., 2007; Stickney et al., 2014b). Patients also preferred the use of simpler language when giving new information (Berkwitt & Grossman, 2015). Availability of interpreters, especially in-person, for non-English speaking families was noted as being vital to effective FCR and communication with families who are not proficient in English (Lion et al., 2013; Seltz et al., 2011; Walker-Vischer et al., 2015). Communication and team collaboration were perceived to be enhanced by FCR. However, according to Whelihan (2015), overall collaboration and satisfaction scores decreased according to health care providers in a NICU after FCR were implemented, while Voos et al., 2011 demonstrated improved overall collaboration in a NICU.

Several studies noted significant concerns from health care providers that the length or duration of rounds would be longer when families participated in rounds (Cameron et al., 2009; Levin et al., 2015; Pickel et al., 2016; Stickney et al, 2014a; Stickney et al., 2014b). However, six studies showed no statistical difference in the length of rounds when families participated (Aronson et al., 2009; Bhansali et al., 2013; Cameron et al., 2009; Ladek et al., 2013; Mittal et al., 2010; Phipps et al., 2007). Two studies reported that rounds were shorter when families participated (Chand, 2011; Rappaport et al., 2012), while Pickel et al. (2016) reported shorter rounds if parents had limited proficiency in English language. Increased time of rounds was associated with the participation of specialist physicians (Aronson et al., 2009); multiple trainees performing a patient exam during rounds (Bhansali, et al., 2013); or rounds that occurred in academic medical centers or with higher average census (Mittal et al., 2010). Pickel et al. (2016) reported longer duration of rounds with family presence, but only when more than two family members spoke or if patients were deemed to be complex. Although Levin et al. (2015) demonstrated longer rounds when families were present, this study noted that family discussion time averaged only 25 seconds, which did not account for the total time difference in rounds.

In addition to length of rounds, physicians and trainees, e.g. residents and students, often cited concerns that FCR would inhibit teaching or educational processes during rounds (Aronson et al., 2009; Cameron et al., 2009; Landry et al., 2007; Lewis et al., 1988; Stickney et al., 2014b), and senior residents were concerned with autonomy (Beck et al., 2015; Rappaport et al., 2012). Phipps et al. (2007) reported no difference in actual teaching time between FCR and non-FCR. Medical students reported that family input was helpful during rounds (Rappaport et al., 2012), and the majority of health care providers reported learning new information about patients from families during rounds (Cameron et al., 2009).

The research by Xie et al. (2015) utilized input from multiple stakeholders that resulted in the development of a tool to improve the process of FCR. An FCR checklist provided a reminder of certain process actions that were deemed to be important to families and providers. Barriers to using the

checklist included higher patient census, multiple interruptions, and the presence of various specialists on the team (Xie et al., 2015). Xie et al. further reported that facilitators to using the checklist included teams' familiarity with the checklist and having clear team roles. Initial piloting of the checklist revealed that teams had higher rates of discussing the patient assessment with families and ensuring the nurse was present, but teams were less likely to ask the team for questions or read back orders in the presence of family members (Xie et al., 2015).

Outcomes of FCR

Parent or family satisfaction was consistently higher when they participated in FCR (Cameron et al., 2009; Kuo et al., 2012; Landry et al., 2007; Latta et al., 2008; Rappaport et al., 2012). More specifically, scores on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS®) were higher on questions relating to doctors listening and showing respect (Kuo et al., 2012), doctors keeping families informed, doctors involving parents in decisions, and nurse communication (Whelihan, 2015). Families reported more accurate knowledge or information about their child and the care plan when they participated in FCR (Kuo et al., 2012; Landry et al., 2007; Latta et al., 2008; Mittal et al., 2010; Phipps et al., 2007). Parents' stress levels were objectively measured in two NICU studies (Abdel-Latif et al., 2015; Voos et al., 2011), however, in both studies, participation in FCR did not demonstrate any difference in parents' stress levels. Parental stress was not objectively measured in other settings.

Families believed that participation in rounds contributed to better quality of care (Drago et al., 2013; Walker-Vischer et al., 2015). Families were more likely to understand their child's inpatient medications when they participated in FCR, and knowledge of discharge medications was also higher if families participated in FCR (Subramony et al., 2012), while Benjamin et al. (2015) demonstrated that family participation in FCR resulted in changes to a child's medication. Parents contributed valuable information that contributed to decisions (Cameron et al., 2009), and Ladek et al. (2013) observed that

FCR provided opportunities for parents to correct their child's medical history or add missing information.

Several studies addressed administrative outcomes. Only one study (Kuo et al., 2012) examined hospital charges for patients whose parents participated in FCR versus patients whose parents did not participate in FCR; this study reported no significant differences in hospital charges. Kuo et al. (2012) further reported no differences in the number of medications ordered for children whose parents participated in FCR versus children whose parents did not participate in FCR. Ladek et al. (2013) was the only study that measured children's LOS and demonstrated a shorter median LOS when parents participated in FCR versus parents who did not participate in FCR. In addition to LOS, time of discharge was examined in two studies. Kuo et al. (2012) found no difference in the time of discharge, but Oshimura et al. (2014) demonstrated that when FCR were conducted, those patients were discharged earlier in the day compared to patients not in FCR. Furthermore, Oshimura et al. (2014) reported that FCR may result in more timely completion of orders for imaging tests, while Chand (2011) and Mittal et al. (2010) reported that FCR may increase efficient use of physicians' or residents' time and overall physicians' workflow.

Discussion

This literature review presents a synthesis of evidence related to structure, process, and outcomes of FCR. Studies represent perspectives of parents and healthcare providers along with objective data. The literature supports the use of FCR for families as well as for healthcare providers.

Structural elements of FCR were addressed and supported in terms of patient- and family-centered care. Parents' preferences for participation in rounds and decisions are consistent with concepts of patient- and family- centered care (Institute for Patient- and Family-Centered Care, n.d.) and recommendations from the AAP regarding the essential role of parents and families in children's care (AAP Committee on Hospital Care, 2012). Because team size reportedly may intimidate families while

impairing productive teamwork, hospitals may need to monitor team sizes and utilize strategies to ensure effective communication with team members regardless of team size. Of note was the recognition in several studies regarding the benefit and value that nursing presence brings during rounds to families and physicians. Sharma et al. (2014) and Pickel et al. (2016) showed that nurse attendance in rounds was enhanced when nurses received notification prior to the beginning of rounds. Xie et al. (2015) utilized a FCR checklist that included nurse participation in order to facilitate greater inclusion of nurses in rounds. Further exploration of strategies to ensure adequate nursing presence on rounds may be useful for resource planning by hospitals.

Despite physicians' and trainees' concerns for added time of family presence in FCR, this was not supported in the studies reviewed. Those studies that demonstrated increased time identified specific contextual factors associated with longer duration of rounds. Multiple contextual factors may affect the actual time in FCR, thus, hospitals that utilize FCR may need to conduct their own site-specific measurements of time and activities during FCR to determine if any changes need to occur that will make FCR more efficient and effective. Chand (2011) outlined a model of reducing waste or downtime while maximizing residents' time, thus it may be possible for hospitals to increase efficiency with time and actions. It is not clear from these studies if staff collaboration improved with FCR based on mixed results from staff members' perspectives as well as objectives measures of collaboration.

This literature review also included studies that addressed outcomes of FCR. Benefits of FCR included higher rates of parent satisfaction with care. Satisfaction with care is a key factor in patient experience that hospitals must monitor because patient experience is being closely tied to reimbursement under the Hospital Value Based Purchasing initiative (Centers for Medicare and Medicaid, n.d.; James, 2012). Although parents or families often reported feeling more comfortable or satisfied with FCR, parental stress was not found to be reduced when measured in the specific setting of NICUs, suggesting that further assessment or evaluation of the impact of FCR on parent stress may be

needed. Patient experience includes multiple factors and elements of care that are not included in this review, however, these studies on FCR support overall positive family experience.

Quality of care and patient safety are fundamental outcomes of any process that must be evaluated. Studies in this review suggest that quality and safety may be improved, including accurate medical information from parents, medication knowledge and adherence by parents, and family education regarding care and discharge plans. Parents also perceived better quality of care for various reasons including that FCR may decrease miscommunication by providing opportunities for healthcare providers to have live in-person communication.

Administrative outcomes, e.g. length of stay, hospital charges, and discharge times were only addressed objectively in a few studies. Although evidence is limited and with mixed results, initial results show promise that administrative outcomes may be improved using FCR. Efficiency of resources may be enhanced by more timely completion of orders or discharges earlier in the day that create more available hospital beds for admissions post-operatively or from emergency departments. Further studies of administrative outcomes with objective measures are warranted to determine how FCR affect administrative factors such as resource utilization and associated costs.

This literature review utilized consensus between multiple readers, thus adding to the validity of study selection and analysis. In addition, CINAHL and Medline are prominent databases and likely returned a maximum number of studies in the initial screening. The primary researcher (DWB) manually reviewed reference lists of all initially identified studies to glean any additional studies that may have related to the research question but that did not appear in the initial queries. This expanded the potential inclusion of relevant studies for review.

The majority of studies in this review were conducted in North America, thus results may not be applicable in other settings. Because health care systems are structured differently between countries, it

is not known how the health care systems may affect the practice of FCR. In addition, the lack of studies in other countries limits understanding regarding the possible influence of cultural factors on FCR.

Diverse inpatient pediatric settings were represented in this review with the exception of psychiatry/behavioral health. Based on this review, there is no evidence to describe the implementation of FCR in psychiatric settings or how families are engaged in daily treatment planning and decisions for their children. Because no studies addressed FCR in psychiatric settings, application of findings to psychiatric settings are not fully possible. In addition, observational studies typically excluded weekends, so the practice of FCR on weekends is not represented or known in the reviewed studies. Any setting that implements the practice of FCR must consider specific contextual factors and patient/family needs that may impact FCR.

Direct input from pediatric patients was limited in this review to only three studies. Feedback and input from direct stakeholders, such as patients and families, is vital in developing and improving systems of care (Committee on the Learning Health Care System, 2013), and collaboration with policy development and research (Conway et al., 2006), yet this literature review demonstrated limited research with actual pediatric patients. Pediatric patients directly experience care, and parents may not always be with children at the hospital (Whose quality is it?, 2004), so although parents may serve as a proxy for their children, parents' input may not fully represent their children's perspectives. Future studies should strive to overcome research barriers with children and engage more patients directly in the research process to help provide evidence for patient value, an essential element of quality of care (Institute of Medicine, 2001), which is consistent with concepts of patient- and family- centered care.

Only a few studies utilized standardized assessments. For example, Kuo et al. (2012) and Whelihan (2015) utilized the HCAHPS®, which is widely recognized as an outcome measure for patient/family satisfaction. However, these studies were conducted prior to the publication of the Child HCAHPS® in 2014. Thus, despite reports of higher satisfaction with certain elements of the HCAHPS®,

results may not reflect perspectives or feedback that is unique or specific to pediatric hospitals and providers.

In contrast, most studies used site-specific questionnaires or interviews, which is not unusual for qualitative research. The strengths of such endeavors were that most studies described a process of establishing content validity or face validity of the questionnaires via review and input from relevant stakeholders or via pilot studies prior to data collection. However, lack of standardized questionnaires or measurement tools limits the generalizability of results to other settings, limits the ability to replicate studies for further validation of results, and limits the comparison of findings other than summaries of main thematic results.

Studies in this review did not necessarily describe the actions or processes of FCR in their respective settings, thus it is not known if the practice of FCR was consistent or identical across settings or providers. Xie et al.'s (2015) checklist of FCR behaviors provides facilitated reminders to standardize the practice of FCR. Cox et al. (2017) demonstrated that the use of the FCR checklist increased the number of FCR actions that were performed, and the use of the checklist was associated with higher family participation and positive healthcare providers' perceptions with safety during handoffs or other transitions. Hospitals may want to consider the use of checklists, and further research may support the use of such tools.

This literature review excluded studies that were published in language other than English, so it is possible that some studies were overlooked; such studies may have addressed some of the concerns with cultural factors that were scarcely represented in this review. Although physicians and trainees reported concerns about negative effects on education, the effect on actual teaching and educational impact was not part of the research question in this review. As such, studies that primarily focused on medical/residency education and training were omitted from this review. Those omitted studies likely contain relevant information for residency education and training in the context of FCR. In addition, such

studies may possess relevant and useful information to hospitals as they manage the complex interaction between patient care, families' needs, and educational or training needs of physician trainees and other healthcare providers.

Conclusion

This literature review addressed elements of structure, process, and outcomes of FCR. Based on the studies in this review, FCR provide many benefits to patients and families without significant burdens on healthcare providers or hospitals. Many studies in this review demonstrated some benefits to healthcare providers as well. Participation in FCR may meet patients' and families' needs for information, participation, and dignity and respect and thus support patient- and family- centered care. Practical suggestions to improve FCR were reported in various studies and may be beneficial for hospitals and providers to review as FCR continue to evolve and develop. Further research could more rigorously assess administrative data for more objective measurements of outcomes such as length of stay or charges. Additional research and strategies to support and integrate cultural factors could also enhance the practice of FCR for diverse patient and family populations. Significant gaps in the literature exist with regards to FCR in psychiatric or behavioral health settings. In addition, although conceptual or philosophical statements regarding FCR are fairly clear in the literature, actual operations of FCR were not described in most studies, thus further research may help to provide more uniform descriptions of process factors or actions that would ensure more consistent definitions and practice of FCR across settings.

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CHAPTER 3

FAMILY CENTERED ROUNDS: OBSERVATION OF DAILY PRACTICE IN A PEDIATRIC HOSPITAL

Introduction

Patient- and family-centered care (PFCC) is a complex concept comprised of values and behaviors. The Institute for Patient- and Family-Centered Care (IPFCC) identifies four concepts at the core of PFCC: *respect and dignity*, *collaboration*, *partnership*, and *information sharing* (IPFCC, 2017). The goals of PFCC are to engage families in a collaborative relationship with healthcare professionals in order to provide the best quality of care and outcomes, lower costs, and higher patient satisfaction with health services. Collaboration with families is also noted by HealthyPeople 2020's goal of family-centered, comprehensive and coordinated systems of care for children with special health care needs (Healthy People 2020). Collaboration with parents or families allows a reciprocal sharing of information about the child, the child's needs and preferences, and the medical care options and recommendations. Because parents and families are typically the primary caregivers for children, involving them in their child's care is essential (Mittal, 2014).

The American Academy of Pediatrics (AAP) further promoted PFCC in 2003 with a call for the inclusion of patients and families in bedside rounds as standard practice to share information and engage families' in care decisions (AAP Committee on Hospital Care, 2003). Since 2003, family centered rounds (FCR) have become commonplace in many inpatient settings; the AAP continues to support this practice (AAP, 2012). This study will further the understanding of the practice of FCR.

Literature Review

Family centered rounds (FCR) are intended to be multidisciplinary discussions at the patient's bedside that include the patient and family members to discuss the patient's care and make decisions (Mittal, 2014; Sisterhen, Blazsak, Woods & Smith, 2007). Components of rounds should ideally include patient and/or family preference for participation, introductions of team members, description of the purpose, summary of the case with relevant test results, discussion of the daily plan and discharge goals

with collaborative decisions (Muething, Kotagal, Schoettker, Gonzalez del Rey, & DeWitt, 2007). Muething et al. (2007) and Sisterhen et al. (2007) further suggested that FCR provide opportunities for efficient communication via the presence of nurses and other healthcare providers who participate in the exchange of relevant patient information, and enhanced communication may then facilitate more effective coordination of discharge planning (Sisterhen et al., 2007). In addition, FCR should provide opportunities for role modeling for trainees by attending physicians regarding effective communication behaviors and interactions with family members and other staff members in the presence of real-time patient issues (Muething et al., 2007).

Beyond conceptual ideas is the need for strategies to operationalize patient-and family-centered care and FCR while having methods to evaluate the efficacy and quality of this approach. One such model, Donabedian's model of quality of care, embodies three factors of structure, process, and outcomes which can be used for this purpose (Donabedian, 2003). S*tructure* refers to organizational characteristics such as physical facilities and equipment; human resources, training or preparation of providers; and policies and performance expectations, e.g. providing residency training, and workload demands. *Process* refers to the actions or behaviors that employees utilize that are related to patient care including diagnosis, treatment and intervention, rehabilitation, discharge planning, and education of patients and families. The combination of structure and process leads to results or outcomes. *Outcomes* refer to changes in the patient's health status and health-related behaviors, changes in patient and family knowledge, changes in patient and family satisfaction, and other administrative or objective outcomes such as length of stay (LOS) and cost.

When Donabedian's model is applied to FCR, structure encompasses multiple factors such as the composition of the healthcare team, space, and location for conducting the rounds. The process of FCR may include scheduling of rounds because the schedule affects availability of families and staff, the frequency and quality of family engagement in the rounds or discussion, and the communication that

occurs between families and healthcare providers. Outcomes may include subjective perceptions of patient and family satisfaction with care, patient or family experience, improvement in health status and reduction in symptoms, changes in patient and family education, discharge readiness, and other administrative outcome measures such as LOS, or decrease in adverse events. For purposes of this paper, structure and process elements will be reviewed.

Structural elements of FCR

At the organizational level, medical education and residency training are typically expected as a component of daily rounds. Various studies reported concerns that FCR reduced emphasis on education for residents and medical students (Aronson, Yau, Helfaer, & Morrison, 2009; Cameron, Schleien, & Morris, 2009; Landry, Lafrenaye, Roy, & Cyr, 2007; Lewis et al., 1988; Stickney, Ziniel, Brett, & Troug, 2014). Expectations for teaching and education may result in tension or conflict with family-centered purposes of FCR.

Phipps et al. (2007) reported a median health care team size of seven members, while Mittal et al. (2010) reported a range of 6-10 members in more than 60% of pediatric hospitals; only 13% of pediatric hospitals had more than ten members (Mittal et al., 2010). Larger team sizes were reported to be inhibiting for families (Beck, Meyer, Kind, & Bhansali, 2015; Carayon et al., 2014; Xie et al., 2015) and health care providers (Mittal et al., 2010). Nurses were highlighted as valuable team members during FCR for patients and/or health care providers (Carayon et al., 2014; Latta, Dick, Parry, & Tamura, 2008; Seltz et al., 2011; Walker-Vischer, Hill, & Mendez, 2015). Nurse presence was reported as high as 69% during FCR (Bhansali et al. 2013) and 73% (Pickel, Shen, & Hovinga, 2016). The structure and composition of teams may vary across settings and may impact the process and outcomes of FCR.

For patients and families, parents prefer that FCR be held in their children's rooms (Beck et al., 2015; Landry et al., 2007; Lewis et al., 1988), and parents reported less anxiety when FCR were conducted in their child's room (Cameron et al., 2009; Ladek et al., 2013). The location of FCR in

patients' rooms ranged from 17% (Balmer, Master, Richards, Serwint, and Giardino, 2010) to 78% (Pickel et al., 2016). Drago, Aronson, Madrigal, Yau, & Morrison (2013) demonstrated that rounds were more likely to occur in patients' rooms when families were present. However, infectious isolation precautions were associated with higher frequency of FCR occurring in hallways outside of patients' rooms (Bhansali et al., 2013). Thus, various factors may influence the location of FCR.

Process Elements of FCR

Average rounding time per patient ranged from 7.9 minutes (Bhansali et al., 2013) to 13-13.5 minutes (Ladek et al., 2013: Phipps et al., 2007); Bhansali et al. (2013) reported no difference in time based on the location of rounds in the hallway versus a patient's room. No statistical difference in rounding time was reported when families participated in FCR (Aronson et al, 2009; Cameron et al., 2009; Ladek et al., 2013; Mittal et al., 2010; Phipps et al., 2007); Chand (2011) and Rappaport, Ketterer, Nilforoshan, & Sharif (2012) reported that daily rounds were shorter after FCR were implemented. Shorter rounds were also reported if parents had limited English proficiency (Pickel et al., 2016). Longer rounds occurred if more than two family members were present or if the patient was deemed to be complex (Pickel et al., 2016), when subspecialists participated in rounds (Aronson et al., 2009), or if multiple trainees examined the patient during FCR (Bhansali et al., 2013). Thus, the time spent in FCR may be impacted by various factors related to the patient, family participation, as well as providers and providers' behaviors.

Family participation is valued and viewed as beneficial by families and the majority of healthcare providers, especially because families may contribute to decisions (Ladek et al., 2013), discuss care (Kuo, et al., 2012) and ask questions (Aronson et al., 2009; Abdel-Latif, Boswell, Broom, Smith, & Davis, 2015; Stickney et al., 2014). Orientation to the process of FCR was desired by families (Levin et al, 1988: Seltz et al., 2011) and patients (Berkwitt & Grossman, 2015) so they could be better prepared to participate. Family participation and presence during daily rounds ranged from 25% (Balmer et al., 2010) to 78%

(Pickel et al., 2016). However, according to Levin, Fisher, Cato, Zurca & October (2015), families with limited English proficiency (LEP) were less likely to participate in FCR and were more likely to be excluded from medical discussions about their children (Lion et al., 2013). Family participation appears to be a valuable component of FCR for families and many healthcare providers.

Communication is a significant element of any rounds process, but especially in FCR that value patient and/or family participation and input. Information exchange was cited as the most, or one of the most, valuable aspects of FCR by parents and by healthcare providers (Latta et al., 2008; Levin et al 2015.; Lewis et al., 1988; Stickney et al., 2014). Healthcare providers reported that parents contribute valuable input and new information during FCR (Cameron et al., 2009: Levin et al., 2015). Ladek et al. (2013) observed that FCR provided opportunities for family members to make corrections or contribute missing information to a child's medical record, while Benjamin et al. (2015) reported that the majority of families' questions were answered during FCR. In other studies, effective FCR provided opportunities for parents or families to learn more about their child's diagnosis and plan of care (Stickney et al., 2014) as well as medications (Benjamin et al. 2015); FCR also provided opportunities to discuss discharge planning (Kuo et al., 2012; Landry et al. 2007, Mittal et al. 2010; Phipps et al. 2007). Effective communication for parents and families also included the use of lay language and less medical terminology (Lewis et al., 1988; Phipps et al., 2007). For parents or families with LEP, the use of interpreters is vital for effective communication during FCR (Lion et al., 2013; Seltz et al., 2011; Walker-Vischer et al., 2015). Additional important behaviors during FCR were introductions of healthcare team members, but this was reported to occur in only 11% of FCR in one study (Aronson et al., 2009). Ensuring the presence of a nurse and discussing the daily assessment with families was also noted as valuable; these behaviors were more likely to occur with the use of a FCR checklist (Xie et al., 2015). Asking teams for questions or reading back orders was also noted as an important activity during FCR, and these were performed less often than other behaviors on a FCR checklist (Xie et al., 2015). Various

elements of collaboration and care planning may occur during effective FCR and may be affected by communication practices during FCR.

Structure and process elements of FCR may be dependent on contextual variables, and many existing studies demonstrate limited information about some factors, or they report inconsistent or differences in other factors. Despite conceptual definitions of FCR, there appears to be variability in practice and implementation of FCR. Bhamidipati et al. (2016) reported a wide variety of definitions and designs of interdisciplinary rounds in general medicine settings for adults. For pediatric settings, only two studies report the use of a checklist or guideline in attempts to standardize FCR (Nichols, Crow, & Balakas, 2015; Xie et al. 2015). Thus, this study aims to more fully understand the practice of FCR in a pediatric hospital setting in order to understand factors related to implementation of FCR. The research more specifically aims to describe the structural characteristics and process-oriented behaviors or actions that comprise FCR.

Methods

Prior to the beginning of this study, the primary researcher (DWB) met with nurse managers and consulted with several physician leaders to discuss the project and obtain their support and buy-in for the study. Nurse managers then alerted their nursing staff about the intended project, while two different physicians facilitated introductions to medical teams. The study was approved by the medical center's Institutional Review Board.

Study Design

An ethnographic approach was used to observe FCR to obtain deeper understanding of the practice of FCR. Ethnographic approaches provide opportunities to describe patterns of behaviors that shape a group or subgroup of people in the naturalistic setting (Creswell, 2007; Fetterman, 2010; Patton, 2015). Ethnography may also be used for program evaluation by examining processes, attitudes, and behaviors in organizations (Patton, 2002). In program evaluation, an ethnographic, descriptive approach

can help identify specific elements that enhance or detract from successful processes (Patton, 2002), can help facilitate change (Patton, 2015), and is a form of applied research which may contribute to future performance improvement initiatives (Maxwell, 1998). Ethnography also allows researchers to observe human interactions that are not easily measured by numerical methods. Standardized observations contribute to reliability of data collection (Bailey, 2007; Creswell, 2007), validity of data (Patton, 2002), and the ability to organize and classify observations.

Setting

The study was conducted at an urban academic medical center with a separate children's hospital, which includes 205 beds. Family centered rounds were observed on four general medical floors – infants and toddlers, school age and burns, adolescent care, and a general pediatric unit that also housed a clinical research unit. Each floor contained 20 single-patient rooms, for a total of 80 beds. Specialty units such as the NICU, PICU, psychiatry, and oncology were excluded from the study due to the highly specialized nature of their services.

Participants

Two general pediatrics teams and one pulmonary subspecialty team were observed during FCR in this study. Participants included four rotations of residents and medical students; attending physicians and fellows rotated on a weekly basis. In addition, a variety of nursing staff members and other healthcare providers were observed during the study period. Participants also included the patients and their family members who were being treated by the medical teams in the study.

Data Collection

The primary researcher (DWB) served as a non-participant observer for FCR on three inpatient services – two general pediatrics teams and one pediatric pulmonary subspecialty team over the course of 14 weeks from January – April 2017. Each team was observed one day per week for a total of 35 days. A FCR observation form (Cox et al., 2014) was utilized to standardize collection and documentation of

the observations. This observation form was based on a checklist of FCR components. Checklists are often utilized in healthcare settings to help ensure standardized processes and thus, improve overall quality (Winters et al., 2009). The FCR observation form (Cox et al., 2014) consists of ten behaviors or actions that represent important actions during rounds; it was developed from multiple observations and interviews with various stakeholders including parents, physicians, and other health care team members in an academic medical center with pediatric services (Cox et al., 2014). The FCR observation form facilitated systematic observations and documentation of actions as well as additional field notes such as content of discussion, positioning of people, computer use during rounds, and size and composition of the team. Total time for each rounding episode was documented along with frequency of teams needing to don gowns, gloves and masks for infection control precautions.

Because this FCR observation form was customized for the hospital where it was developed, the observation form was slightly adapted for this study to indicate which medical service was being observed as well as to indicate the initials of the observer. A column for reminders of the FCR checklist was removed because that column was not applicable to this observational study. The adapted version of the observation form is in Appendix 3.A. Prior to data collection, the FCR observation form was piloted by the primary researcher (DWB) and another observer (SM) on at least 13 FCR encounters and established inter-rater reliability of at least 80%; this was consistent with guidelines for the original FCR observation tool (Xie et al., 2012).

Each patient encounter with FCR was assigned a numerical code on the observation form. Patients' participation in FCR was considered only for patients who were at least six years old. Development of cognitive, language and social skills at this age are typically adequate for attending to conversations with others (Papalia & Martorell, 2015). Privacy and confidentiality was maintained at all times. No dates or other identifying information about patients or healthcare providers was documented on the observation form. Healthcare team members were noted by their roles and

disciplines, but not their names. General comments about interventions and context were documented, but no specific diagnostic information was included.

Standardized observations and field notes allowed for multiple sources of data collection, which contributed to a more comprehensive understanding of the behaviors being studied. Additional field notes and daily summary memos included comments regarding the physical environment, body language, expressed emotion, and miscellaneous observations about team communication. These social and physical environment elements provided a more holistic and detailed description while facilitating awareness of factors that contributed to the overall interactions and behaviors (Bailey, 2007).

Data Analysis

Observations and other comments from the observation form were transferred to an Excel spreadsheet and coded for analysis. Excel data was imported into SPSS version 24 for analysis. Data analysis included descriptive statistics such as frequencies, percentages, or counts. For continuous variables, student's t-test was used to examine differences between two samples, and Analysis of Variance (ANOVA) was conducted to examine differences between more than two groups or samples.

Daily summary memos were coded using HyperRESEARCH version 3.7.3. Narrative comments from each patient encounter during FCR were coded using HyperRESEARCH version 3.7.5. For both memos and narrative comments, codes were based on the pre-determined concepts of patient- and family-centered care, e.g. respect and dignity, participation, collaboration, and information sharing; other codes emerged during review of the documents. The code reports were then reviewed and analyzed, using content analysis to determine themes. Triangulation of qualitative results was achieved from the memos and field notes or comments from observations, along with review between the primary researcher (DWB) and another researcher (PD) to achieve consensus or congruity of analysis.

Results

Results include descriptive statistics and qualitative observations. A total of 304 patient encounters were observed during FCR. Of those 304 patients, 27 were seen in rounds more than once due to a prolonged LOS or readmission during the study period; thus, observations reflect 277 unique patients. One patient encounter was excluded from observations to respect the patient's privacy and confidentiality because the primary researcher (DWB) had a prior acquaintance with the patient and family; this patient encounter was only included in the overall daily census for the medical team and the total time for the rounding episode on that day. Ages of observed patients ranged from 5 days to 21 years; 98 (32.6%) were infants aged 0 – 12 months; 84 (27.9%) were aged 1-5 years; 46 (15.3%) were aged 6-11 years, and 73 (24.3%) were 12-21 years old. Age was missing for 3 patients. Males comprised 55.6% of the patients who were observed. Reasons for admissions represented a range of conditions including asthma exacerbations, cystic fibrosis, bronchiolitis, respiratory syncytial virus, fevers, gastrointestinal virus, metabolic disorders, and others.

Structural Elements

Results related to the structure of FCR address the following:

- Expectations for time and workflow
- Location of FCR
- Team caseload and team size
- FCR team members and frequency of participation in FCR
- Qualitative observations related to
    - Competing demands on the medical teams during FCR
    - Nurses' presence and participation in FCR
    - Role modeling and teaching of residents and medical students during FCR

FCR were conducted every weekday and began at approximately 8:00 AM. FCR were expected to be finished before 10:30 AM when hospital-wide morning report was scheduled, which senior residents were expected to attend. Medical teams followed pre-assigned different workflows or orders of floors to visit for FCR; workflow plans were intended to prevent multiple teams rounding concurrently on the same floor which could impact physical space but also availability of nurses and other staff. The

location of FCR occurred in only patients' rooms 142 (36.7%) times, only the hallway 127 (41.8%) times, and both hallway and patient room for 30 (9.9%) encounters. Five (1.6%) encounters occurred in conference rooms due to sensitive issues, e.g. legal issues. However, when family members were present (n = 187 encounters), the majority (64.3%) of FCR encounters occurred in the patients' room, with 24.7% occurring in hallways, and 11.0% in both the patient room and hallway.

Distribution of observations, caseload sizes, and team sizes are displayed in table 3.1. The pulmonary team's average caseload was smaller than both of the general pediatrics teams [F (2, 32) = 10.62, p = 0.003]. The pulmonary service had smaller team sizes than both general pediatrics teams, and pediatrics team A was slightly smaller than pediatrics team B [F (2, 301) = 42.38, p=0.000]. The two general pediatrics teams typically included two senior residents, two first year residents or interns, and several medical students. Medical students did not participate in FCR with the pulmonary specialty service.

Table 3.1. Team Characteristics

	Days	Patients	Daily Caseload Size			Team Size	
Team	observed	n (%)	Mean	95% CI	Range	Mean	95% CI
Pediatrics A	12	116 (38.2)	9.83	(8.78, 10.89)	(8, 15)	8.35	(7.95, 8.75)
Pediatrics B	11	110 (36.2)	10.0	(8.58, 11.4)	(7, 15)	9.46	(8.91, 10.02)
Pulmonary	12	78 (25.7)	6.5	(5.26, 7.74)	(5, 11)	6.33	(6.08, 6.59)
Total	35	304 (100)	8.74	(8.0, 10.0)	(5, 15)	8.24	(7.94, 8.53)

Table 3.2 displays the frequency of each discipline's presence during all FCR when at least one person from the discipline was present. Subspecialty medical services joined the general pediatrics teams for 25 (8.2%) FCR. An attending physician was always present in the pulmonary specialty FCR. An attending physician was present for 105 (46.5%) of the 226 general pediatric FCR. One of the general pediatric teams included a certified registered nurse practitioner (CRNP), and the pulmonary team included a case manager. Other team members joined FCR as needed and/or available, including case managers assigned to the specific floor or unit, and clinical customer service coordinators (CCSC) who who support strategic initiatives of service excellence and the patient experience.

Table 3.2. Healthcare Provider Presence during all FCR (n=304)

Discipline	Patient encounters n (%)
Attending physician	183 (60.2)
Fellow[a]	78 (25.7)
Senior Resident	295 (97.0)
First Year Resident (Interns)	298 (98.0)
Medical Student	170 (55.9)
Nurse	260 (85.5)
Social Work	84 (27.6)
CRNP[b]	76 (25.0)
Case Manager[c]	129 (42.4)
Clinical Customer Service Coordinator	68 (22.4)
Other	129 (42.4)
Pharmacist/pharmacy student	49 (16.1)
2nd year resident from another hospital[a]	34 (11.2)
Nursing student	13 (4.3)
Subspecialty – Genetics	13 (4.3)
Subspecialty – Endocrinology	8 (2.6)
Interpreter	5 (1.6)
Subspecialties (ENT, Neuro, Adolescent Medicine, unknown)	4 (1.3)
Respiratory therapy	3 (1.0)

Notes: [a]Pulmonary rounds only.
[b]One general pediatrics team only.
[c]Included pulmonary team and case managers assigned by floor/unit.

Medical Teams Face Competing Demands. Physicians and their trainees managed multiple demands on their time during FCR. Insurance issues often affected decision-making regarding discharge planning and other logistics including approved medications, LOS, and transfer to less acute facilities. Such insurance issues often presented as barriers that required time and attention to clarify information or policies so that teams could plan accordingly. Other tasks that required time and attention during FCR included writing orders or following up with specialty consults and/or test results, all of which also required individual follow up with families later in the day. Several times medical teams did not complete rounds prior to morning report, which necessitated rounding with the remaining patients later in the morning. Medical teams also faced administrative pressure to write discharge orders by 10:00 AM. Medical teams were also responsible for examining and admitting new patients from the emergency department as needed; this occurred several times during the study period but not every day.

Nursing staff presence during FCR was challenged by competing responsibilities. Medical teams almost always notified the front desk upon arrival to each floor in order to alert nursing staff that they were ready to begin FCR. However, teams seldom waited for the nurse to arrive before beginning

discussion with families. As a result, nurses frequently arrived several minutes after FCR encounters began, or they sometimes left a room early to attend to other needs. In such cases, it was common for a nurse to approach the medical team in the hallway for a FCR update while the team was traveling in between rooms. In addition, the nurse who participated in FCR was often a team leader or charge nurse, and not the patient's bedside nurse. On several occasions, at least two medical teams were rounding concurrently on the same floor; during such instances, availability of nursing staff during FCR was limited due to the effort of covering multiple teams while providing direct patient care. Nursing staff to patient ratios were not collected or analyzed during this study. Despite the challenges, a nurse was present for part of patient encounters during the majority of FCR.

FCR provide opportunities for attending physicians to role-model or teach elements of patient- and family-centered care. On multiple occasions when attending physicians participated in FCR, they were observed to engage in teaching or giving suggestions to residents and medical students while walking between patients' rooms or role modeling behaviors during patient encounters. Some attending physicians demonstrated reassurance to visibly distressed parents, and explicitly expressed concern for parents' sleep and rest while at the hospital. When talking with residents and medical students in between patients' rooms, attending physicians often stressed the "need for family perspectives;" using more of a "conversational" style, especially with adolescent patients; addressing how families are coping with a child's LOS; and initiating difficult discussions, e.g. palliative care, with families. Additional examples included asking parents for their preferred name, e.g. "what would you like the team to call you?"; sitting and making eye contact with parents; asking a patient's permission to touch his/her body during the exam; socially interacting with a child; and providing parent education regarding illness and prevention at home. Another example of teaching was voicing the importance of completing rounds with "minimal disruption to the family, especially with a young child." When teaching occurred with specific examples or suggestions, residents and medical students were observed to

implement such strategies in the successive patient encounters during FCR on that day. Attending physicians also often remarked on the importance of time management.

Process Elements

Results related to process factors include the following:

- Patient and Family Participation in FCR
- Time or duration of FCR per patient
- Activities and tasks completed during FCR in the presence of families
- Qualitative observations regarding
    - Family and/or patient input and teams' engagement strategies
    - Communication with families
    - Communication between multiple providers
    - Interpersonal rapport with families and/or patients
    - Impact of FCR schedules on families' sleep and daily activities
    - Personal space and physical environment
    - Team introductions
    - Language barriers during FCR

Participation in FCR by Patients and Family Members. Of the 304 observed patients, 119 patients were 6-21 years old. As seen in table 3.3, the average age of this subgroup of patients was 13.1 years; of those patients, 35.3% participated in rounds while 15.1% declined to participate when invited. Patients who participated in FCR were older than those patients who declined to participate [$F(3, 115 = 3.51, p = 0.012$]. Some patients gave no reason for their lack of interest in participating; several patients were asleep and did not awaken or respond to the team's attempts to interact with them. One patient clearly indicated that he/she did not want to hear "any scary stuff," and another patient had already expressed his/her preference to not participate in FCR during the pre-rounding sessions with the resident or intern.

Table 3.3. Participation in FCR by Patients ≥ 6 years old

		Patient Age (Years)	
	n (%)	Mean	95% CI
Participated	42 (35.3)	14.0	(12.8, 15.1)
Declined to participate	18 (15.1)	10.2	(8.3, 12.0)
Not invited to participate	37 (31.1)	13.0	(11.4, 14.5)
Unable to participate[a]	22 (18.5)	13.9	(11.5, 16.4)
Total	119 (100)	13.1	(12.3, 13.9)

Note: [a] Developmental disabilities and delays.

Participation by any family member occurred in 187 (61.5%) encounters of FCR. Family participation is shown in table 3.4. Of these encounters, both parents participated in 37 or 12.2% of FCR. Mothers were the most frequent participants in FCR. Other family members typically included grandparents or an aunt or uncle. Of the 17 mothers who did not participate, two were not invited to participate in rounds; no reasons for this were obtained.

Table 3.4. Family Participation in FCR (n=304)

	Participated n (%)	Did not participate n (%)	Not Available n (%)
Mother	150 (49.3)	17[a] (5.6)	137 (45.1)
Father	66 (21.7)	9 (3.0)	229 (75.3)
Other	15 (4.9)	12 (3.9)	277 (91.1)

Note: [a]Two mothers were not invited to FCR

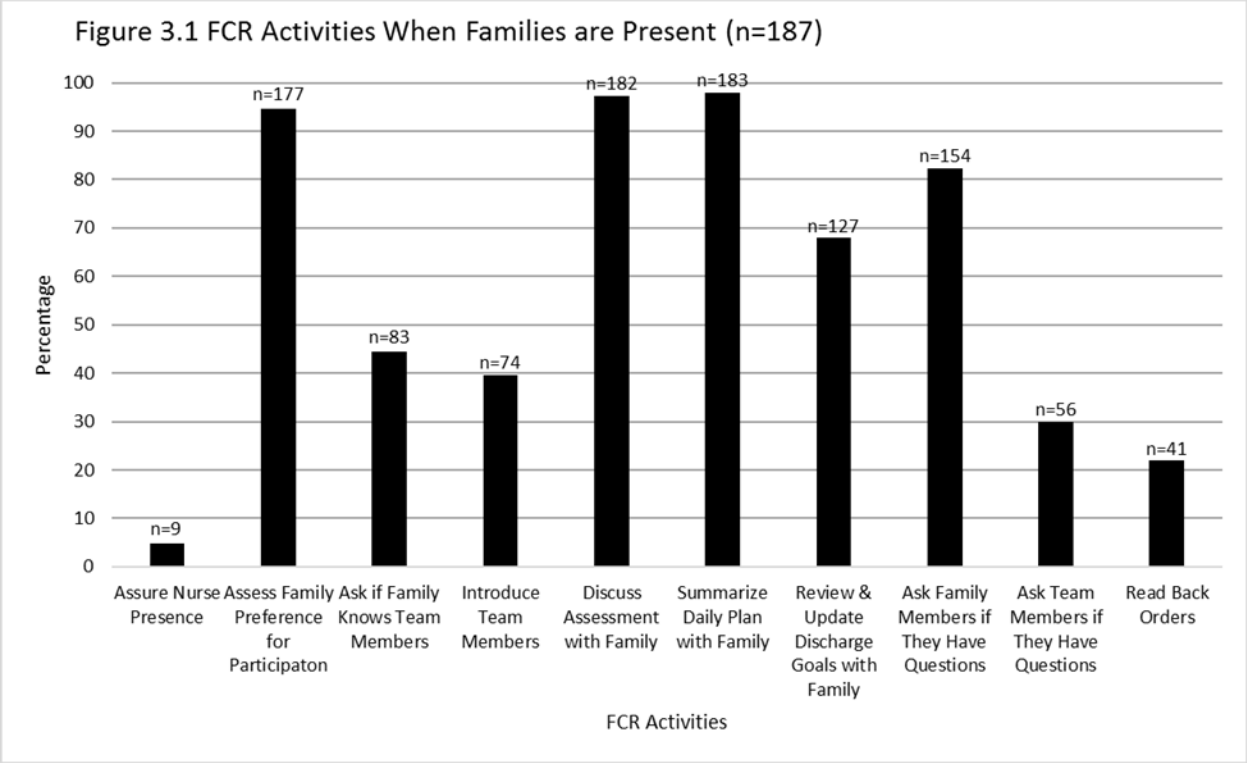
Time per patient. The average amount of time that teams spent per patient during FCR was 10.6 minutes, with a median of 10 minutes. Results are displayed in table 3.5. When families participated in FCR, the average time per patient was 3.30 minutes longer than FCR encounters when no family member participated [t(294.06) = -4.85, p=0.000]. When personal protective equipment (e.g. gowns, gloves and masks), for droplet precautions and infection control, was worn (99/250 encounters), the mean time of FCR per patient was 4.09 minutes longer [t(164.494 = -4.63, p=0.000] than when it wasn't worn.

Table 3.5. Minutes per Patient during Family Centered Rounds

	n	Mean	95% CI
All FCR	304	10.61	(9.89, 11.33)
With Family Participation	187	11.88	(10.90, 12.87)
No Family Participation	117	8.58	(7.66, 9.50)
difference		3.30	(-4.64, -1.95)

Activities during FCR. The frequency of FCR activities from the observation form are displayed in Figure 3.1; only those FCR encounters in which family members participated are included in this table. The activity of asking families for questions includes FCR encounters when families initiated questions during rounds. Although inclusion of the family in communication occurred the majority of the time, communication among the team members to clarify plans or read back orders in the presence of families occurred infrequently. However, teams were observed to ask each other questions and to clarify orders, as needed, while walking in between patients' rooms but outside of the presence of

families. In addition to the activities displayed in Figure 3.1, computer use with families was recorded as occurring in 21 (11.2%) of encounters; the most frequent reasons for the computer use were to obtain and share recent vital signs or lab results, to examine X-rays or other images with parents, and to confirm parents' preferred outpatient pharmacy for discharge planning.



FCR usually provided opportunities to incorporate family input and values. Examples of soliciting family values and goals was when the team would ask the parents specifically for their goals for their child during this hospital stay, or "what works for you at home?" Team members occasionally encouraged parents to "jump in" with additional input or questions. In addition, parents were often asked if they were "comfortable" with plans. When the healthcare team was aware of patients who had special needs due to, for example, autism spectrum disorder, the team would ask parents to describe the child's typical reaction to interventions and request parents' input regarding helpful approaches to minimize stress for the child. On a few occasions, the healthcare teams sought input from older children or adolescents about how they were managing a chronic condition at home and also sought patients'

input about possible changes to treatment. If parents were not present for FCR, healthcare team members frequently incorporated parents' prior reports of medical history or presenting symptoms into FCR discussions. Thus, parents' input was usually included whether or not they were present for FCR.

Families' preferences and needs were often considered for discharge planning. Based on each child's contextual situation, discharge discussions may have included nutritional goals, medications at home, medical equipment and parent training if needed, possible discharge dates, and symptom management after discharge. Less often, the patient's return to school or activities was discussed. Several different parents asked for approximate discharge times due to the logistics of coordinating transportation with their family or professional responsibilities. Medical teams were observed to frequently request the family's preferred outpatient pharmacy in preparation for discharge. When discharge medications were ordered from the hospital's outpatient pharmacy, a team member occasionally offered to alert parents when the prescription was ready for pick-up to avoid waiting in the pharmacy. Teams also offered to schedule outpatient appointments with pediatricians or other outpatient providers, and teams also asked families for preferred days and times for appointments due to families' logistics of transportation, other siblings in the family, or other responsibilities at home.

Parent or family participation was valued, but approaches to engage families were inconsistent. Healthcare team members almost always checked a patient's room to determine family member availability and interest in participating in FCR. Teams did not often ask if parents preferred meeting in the hallway or patient's room. On several occasions, teams willingly accommodated families by conducting FCR with parents via telephone if parents were not available in person. When parents participated, healthcare teams frequently asked them for their input. At times medical providers were unsure about waking a family or patient for FCR but would quietly knock on the door and invite parents if they were available. In two instances, signs had been posted on a patient's door to indicate that parents wanted to be awakened in order to participate in FCR. The primary researcher (DWB) did not

observe any orientation or explanation of FCR to parents except with one rotation of residents; in these few instances, FCR began with a physician, resident or medical student providing a brief overview of the purpose of FCR and ways parents or families could participate.

Patient Engagement in FCR varied. Sometimes the medical team directly engaged patients, especially adolescents or older children, in discussions or by asking them questions about symptoms, medication, and plans. However, this was inconsistent. Often if parents or family were not available, the medical team let the patient sleep and they conducted FCR in the hallway. At other times the medical team talked with parents and not the patient; parents then were observed to directly convey the information or question to the patient in the presence of the FCR team.

Although the healthcare teams often interacted with patients during FCR, 31.1% of children ≥ 6 years old were not invited to participate in FCR. The most common reason was that no family was available in the patient's room, thus the team opted to round in the hallway without the patient. In other cases, patients and/or family members were asleep, and the team opted to not awaken them. In a few cases, a senior resident or intern talked individually with the patient or family and had no further team discussion. In several cases when patients were not invited, the primary researcher (DWB) observed the pediatrics team and a subspecialty team conducting collaborative discussions in the hallway that did not include the patient or family. In only a few cases, the team opted to not invite the patient to FCR due to the patient's behavioral/psychiatric status and/or presence of a security guard in the patient's room.

Communication with families during FCR varied in content and quantity. Discussion with patients or families typically included medical history, diagnosis and recent symptoms, vital signs and imaging or laboratory test results. The patients' daily plan was also consistently discussed and often included dietary and nutrition goals, medication changes if needed, pending tests or imaging, and symptoms that required ongoing monitoring. During multiple FCR encounters, the healthcare team

members provided education to patients and/or families about diagnoses, symptoms, medications, expected progression of symptoms and recovery times for acute conditions, as well as further management of chronic conditions. Family members frequently initiated questions to healthcare teams who readily responded and answered questions. However, a few times families seemed uncertain if asking questions was acceptable. A mother initiated a few questions and then asked the team if it was "okay" to ask questions during FCR; the team reassured her that asking questions during FCR was welcomed. On other occasions, team members were observed to provide positive feedback to parents about their "good" questions and input. In general, healthcare teams often answered questions that patients or parents/family members initiated. However, some providers used a mix of medical terminology and jargon. For example, several times teams mentioned "medication taper" as a plan, and at least once, a parent asked the team to explain the phrase. Several healthcare teams used the word "dispo" instead of "discharge." Occasionally, acronyms or numerical lab results were explained, but not consistently. Other providers used more laymen terms and simpler explanations, i.e. reporting lab results as "good" or "within normal limits" vs. giving exact lab results. One particular rotation of residents and medical students explicitly explained to a parent, "for the team I'll give numbers" and then explained test results for the parent using lay terminology of "within normal limits." In another encounter with this same FCR team, a healthcare provider asked a parent if he/she preferred "milliliters or ounces" when discussing care plans; this was unusual as healthcare teams seldom asked families for their preference with terminology.

Some providers used clear explanations of goals for patients, i.e. they wrote goals on the dry erase white board in the room and/or drew pictures of cups to demonstrate fluid intake goals. Other items that were occasionally listed on these white boards were pending tests or images, so they could be checked off when completed. Parents or families were occasionally, but not consistently, encouraged

by healthcare providers to use the white board to share their own questions or thoughts and ideas with the team.

Discharge planning was more likely to be discussed if discharge was pending within the next two days. Discharge planning was seldom addressed if the expected LOS was more than a few days unless there were specific equipment needs or parent education protocols to follow. When discussing discharge plans, the primary researcher (DWB) observed that sometimes discharge times were presented vaguely, e.g. “this evening” but then another healthcare team member would report during the same FCR encounter that discharge could occur after the next medication dose, which would occur within only a few hours or by mid-day. Parents or families would sometimes request more specific discharge dates and times, especially when they needed to coordinate transportation or other responsibilities at home. Often discharge was explained as being dependent on symptom reduction or changes in progress, and thus with a range of possible discharge dates.

Inconsistent communication between subspecialists and general pediatric teams affected participation and information sharing with families. On various occasions a subspecialty team met with a general pediatrics team for a scheduled collaborative FCR discussion. However, in almost all of these situations, the two medical teams met in the hallway, and families were seldom invited to these discussions if they were available. In contrast, a different subspecialty team was observed to collaborate with general pediatrics for various patients, and these collaborative discussions usually occurred in the patients’ rooms with families if they were available. In several situations, the healthcare team members asked a parent for an update from another subspecialist who had already examined the patient earlier in the morning. General pediatrics teams would usually skip a patient’s FCR encounter if a specialist was already in the room with the patient or family; in these instances, the pediatric team might return to the patient’s room before leaving that unit, or they commented that someone would follow up with the parent individually later in the day. On only one occasion, a healthcare team member encouraged the

rest of the team to enter the patient's room to discuss care with the specialist already inside the room, and the specialist welcomed the team to join him/her in a collaborative discussion. In one extreme example, a subspecialist drew a parent out of the child's room during FCR. In this case, when the healthcare team progressed to the next patient, one healthcare provider remained behind for an individual discussion with the parent to share information from FCR and to obtain updates from the parent regarding the subspecialist's visit. Another example was a patient whose medical record revealed notes from two different subspecialty services, each of which referred to the other for changes or progression of treatment; this lack of communication created a delay in treatment but also required the pediatric team to spend time following up with the specialists to clarify the issues before they could update and discuss plans with the patient and family.

FCR usually provided opportunities to establish rapport and provide feedback to parents. During FCR, some providers would ask a patient or parent for his/her preferred name. Some providers also engaged in social interaction with patients, e.g. talking with a patient's stuffed animal or toy, asking about school or other interests and activities. Healthcare teams often provided positive feedback or reassurance to parents regarding parents' management of symptoms or chronic conditions at home. Healthcare teams occasionally commended parents for asking good questions, providing additional input, or advocating for their child. On several occasions, medical teams demonstrated awareness of significant family events, e.g. birthdays for patients or siblings, and they encouraged celebrations when possible. However, these practices did not happen consistently; for example, one provider was heard to express frustration with his/her perceived "waste of time in chit chat" about a child's upcoming birthday party. Overall, the pulmonary subspecialty team appeared to have an advantage over the general pediatrics teams with patient rapport because their patients were often known to the providers due to ongoing visits to outpatient specialty clinics for management of chronic conditions.

Respect for patients' and families' sleep and daily schedules may conflict with FCR. Healthcare team members would usually quietly knock and open a patient's door to check if the patient or family was available and awake. On multiple occasions, the healthcare team apologized to patients and/or families when awakening them for FCR. One day, an attending physician expressed surprise that several parents were asleep and declined to participate in FCR. On other occasions, a recently-awakened mother apologized to the team because she was not "fully dressed" when FCR began, and another parent asked for approximate timing of procedures that day so that she could plan when to take a shower. If the healthcare team was aware of an overnight or late-night admission, the team would conduct FCR without the family so that the patient and family could sleep. Often if parents or family were not in a child's room and the child was asleep, the healthcare team would not awaken the child, including adolescents, but would conduct FCR in the hallway without the child.

Respect for the personal space and physical environment varied. Healthcare providers displayed various behaviors when entering patients' room or when conducting FCR in hallways. Providers were observed to always knock on a patient's door prior to opening the door. Sometimes a provider asked permission to turn on a light in a room where a patient or family was asleep, but not always, and sometimes the light was turned off after FCR but not always. Other times providers sat on the edge of the patient's bed or parent's sofa bed without asking permission. Some providers asked permission to touch a patient or to pull back the child's blanket or gown during FCR examinations, yet other providers proceeded with such actions without asking or alerting the patient. On several occasions when FCR were conducted in the hallways, other family members or employees would walk near or through the team "huddle," or FCR were conducted in hallways near a family kitchen where discussions might have been overheard.

Team Introductions were inconsistent and followed no standardized process. When introductions occurred, team members individually introduced themselves with their respective role.

However, more often the primary provider, e.g. resident or medical student assigned to the child's case, would introduce himself/herself and then make broad or general comments such as, "I'm sure you know [or remember] everyone here" or "here's our entire team" with no individual introductions. During one FCR encounter, a parent commented that he/she noticed new or different people in the child's room and he/she then requested introductions of the team members. A one-page handout with the medical teams' faces, names, and respective roles were often, but not consistently, distributed to families at the beginning or end of FCR with no additional verbal introductions; these handouts contained information about only the medical team of attending physicians, residents and medical students with no additional team members, e.g. nurses, case managers, social workers, etc.

FCR may accommodate language barriers based on staff language skills or advanced planning. On several occasions, FCR were translated into the family's preferred language via a healthcare team member who was bilingual. In addition, hospital interpreters were scheduled in advance for several FCR encounters, and on at least one encounter, an interpreter was obtained via telephone. Occasionally a family member would interpret FCR for another family member. However, on a few occasions, interpreters were not available or had not been scheduled; FCR were very brief, and the team commented that someone would follow up with the family individually later when an interpreter arrived. The primary researcher (DWB) observed apparent confusion between team members regarding the process for arranging an interpreter or who was responsible for scheduling an interpreter. On one occasion a team member suggested using a popular online translation program, however it was noted by another team member that this online program was not certified for translation.

Discussion

Healthcare teams demonstrated high interest in family participation and made efforts to engage families in most FCR encounters; the frequency of family participation was within the reported ranges in the literature. Healthcare teams' high frequencies of discussing current patient status and daily plans,

answering questions and inviting questions from families, and the emphasis on incorporating family preferences and needs into discharge planning suggest that this hospital's culture respects families' input and values their participation in children's care. However, the uncertainty of waking parents and inconsistent communication strategies with families may indicate the need to re-evaluate processes and scheduling of FCR. The isolated use of signs on patients' doors regarding families' desire to be awakened for FCR suggests that similar strategies could be utilized more consistently; this could possibly serve as a reminder to help ensure that parents or families received orientation to the FCR process, something which occurred infrequently in this study's observations. Posting signs on patients' doors is also suggested to help communicate families' preferences for participation in rounds (Cincinnati Children's Hospital, n.d.).

Family centered rounds in patients' rooms represented opportunities for participation by families and/or patients. The location of FCR was more often in the patients' rooms when family members were present; this is consistent with Drago et al. (2013). Average time per patient during FCR was longer when families participated. This is inconsistent with reports from the literature that demonstrated no differences with family participation when adjusted for specific contextual variables. Team size in this study was also consistent with team sizes as reported by Mittal et al. (2010) and Phipps et al., (2007). Team composition was comparable to team members as described in the literature, however, team composition should be considered in the context of each setting. Of note is that almost all FCR included senior residents or interns, while attending physicians' presence was much lower for the general pediatric teams. This may reflect a hospital value of allowing senior residents more autonomy and independence as part of their clinical educational experiences; residents desire for autonomy has been reported by Rappaport et al., (2012). Because attending physicians were observed to demonstrate and/or teach aspects of patient and family-centered care during FCR with an immediate real-time application of feedback, the presence of attending physicians may positively influence the

practice of FCR and development of competency with patient-and family-centered care for future physicians.

Patients who chose to participate in FCR were more likely to be adolescents. Transition to adult medical care and autonomy are essential and are recommended by the American Academy of Pediatrics ([AAP], 2011), which suggests that transition could begin as early as 12 years old. The AAP (2011) encourages healthcare providers to help adolescents learn and develop self-management skills and participation in maintaining their own health. However, because some adolescents were not invited to participate in FCR, they may have less opportunity to develop responsibility for their own care as they transition to adulthood.

Nurse presence was higher than reported by Bhansali et al., (2013) or Pickel et al., (2016), suggesting that the practice of FCR in this setting supports nursing participation. Of concern, however, is that nurses often missed part of the FCR encounter because medical teams seldom waited for nursing staff before FCR discussions began and/or nurses did not remain with the team for the entire encounter due to caring for other patients' needs. Although nursing presence was high and was often represented by nursing team leaders or charge nurses, these nurses may not be as familiar with the patient and the family. The study did not obtain feedback from nurses or other healthcare providers on FCR, thus it is not known how nurse attendance patterns affected FCR or patient care. Sharma et al. (2014) demonstrated that use of hands-free communication devices, e.g. pagers, increased nursing presence on rounds, although the rate was comparable to the rates of the current study. More recently, Aboumatar et al. (2015) reported that nursing-led rounds were frequently used at hospitals with higher performance on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS®) survey. Thus, other strategies to enhance nursing presence may be beneficial.

Providers' behavior appeared to vary in communication style, demonstration of respect, and sharing of information. The use of medical terminology and jargon may limit patients' or families'

understanding of a patient's condition or treatment plan. In addition, although only a handful of FCR required interpreters, patients and families with limited English proficiency represent a niche population that needs to be fully engaged in FCR and care planning to ensure they have essential information and knowledge to effectively care for their children and to help ensure quality of care. Hospitals may need to emphasize hiring bilingual staff when possible and/or ensuring a clearly defined process for obtaining available interpreters as needed. Various effective verbal and non-verbal communication strategies were observed during FCR, e.g. using the white board; soliciting input from families and patients; explaining terminology or test results in lay language; being more aware of the patients' personal space and environment in patients' room; and acknowledging patients' or families' names, personal needs as well as personal interests and activities of daily life. These strategies could be implemented more consistently by providers in FCR to increase respect and dignity as well as more effective information sharing.

Of significant concern in this study was the limited communication between multiple subspecialists and healthcare teams or limited use of techniques such as reading orders back during rounds that are known to facilitate communication and avert errors. Families appeared to be excluded from some collaborative discussions between healthcare teams, which may limit their understanding of their child's condition and care and also their ability to participate in discussions and decisions. In addition, when families were expected to provide real-time updates between subspecialists and general pediatric teams, this could lead to misinformation or miscommunication. While it is not practical for multiple providers to conduct FCR collaboratively for all patients, multi-specialty discussions may be warranted for integration with FCR, when possible, to enhance information sharing and participation with families and between providers.

The competing demands for time and attention during FCR present barriers to effective time management and workload management for healthcare teams. It is not known if these pressures

affected some of the activities or behaviors during FCR, especially those that occurred less frequently. Observations in this study were based on a FCR checklist; this checklist is not currently used by the hospital in this study. However, Cox et al. (2017) reported that using the FCR checklist enhanced performance of FCR activities. This suggests that a FCR checklist may help ensure that healthcare teams complete essential tasks during FCR. Prompts for family and patient engagement could be added to such a checklist to help facilitate more consistency in behaviors related to patient- and family-centered care. In addition, time and task completion may be more efficient when healthcare team members, including attending physicians, conduct FCR together, thus eliminating some of the additional follow-up individual communication that may otherwise be required for final decisions about care.

This study and its methodology spanned multiple rotations of trainees as well as providers, thus a broader scope of practice and behaviors was observed. This broad span of time and providers also helped to ensure providers' anonymity. The primary researcher (DWB) is not an employee of the organization which may have ensured more objectivity of observations. The standardized observation form ensured more systematic collection of data. The study also represented all ages of children treated in this hospital.

No study is without its limitations, however. This study was conducted at a single hospital and included only one subspecialty service; thus, results may not generalize to other hospitals, subspecialty services or the broad array of subspecialty providers, nor to the specialty units, e.g. the neonatal intensive care unit. This study did not include weekends, which is also a weakness in the literature about FCR. This study also did not collect racial/ethnic information, diagnoses or LOS data on each child seen during FCR but instead, the study assumed a broad representation of patients in FCR. In addition, seasonality of the study period during winter months may have skewed the inpatient population demographics due to seasonal rates for influenzas, bronchiolitis and related respiratory illnesses; a

longer study period may have resulted in a broader representation of diagnoses that are treated in this setting.

Conclusion

This study demonstrated various structural and process elements of FCR in a pediatric hospital. FCR consistently engaged families in discussions about the child's current status and daily plans, and FCR also frequently addressed families' questions. Healthcare teams valued the participation and input of families during FCR, but communication and strategies to engage families varied across providers. Respect and dignity as well as information-sharing during FCR were demonstrated but not consistently. Strategies for improvement should be considered and may include enhancing healthcare provider behavior through additional training, simulations of FCR, using a FCR checklist, or exploring methods to increase nursing participation in FCR. Family and patient participation may be enhanced by providing orientation to FCR and posting signs on patients' doors as well as by being more intentional with patient participation, especially with adolescents. Further research should explore how and if FCR are conducted on weekends and how families and patients are engaged in decision-making and information sharing during the weekends. This hospital demonstrates many strong practices and values for patient- and family-centered care, however, more consistency in behavior is needed to help ensure better quality of the practice of family centered rounds.

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Appendix 3.A. Family Centered Rounds Observation Form

Observation Day # _____; **Observer:** DWB|Other: _____; **Service:** peds | pulm **Round Number:** _____;
 # Family members: _____ **Fam:** Mom|Dad|Other: _____ **Patient Participation:** Yes|No **Location:** Patient room |hallway |Other _____
#HCT members: _____ Att.,_____ Fell.,____ PL-3,_____ PL-2 _____; PL-1_____; MedSt._____Int.,_____ RN,_____ SW,_____ Pharm_____ others_____

Checklist Activities	Order	Done?		Notes	Pt. Age: _____ Pt. Sex: M/F
		Y/N	Who		Observer notes
a. Ensure Nurse is present		Y/N			
b. Check family preference for rounds		Y/N			
c1. Ask if family knows everyone on team		Y/N			
c2. If not, introduce unfamiliar team members and roles		Y/N			
d1. Discuss assessment with family		Y/N			
d2. Summarize plan for day with family		Y/N			
e. Review and update goals for discharge with family		Y/N			
f. Ask family for questions		Y/N			
g. Ask team for questions		Y/N			
h. Read back orders		Y/N			
Begin: _____ End: _____	Use of computer for interacting with patient and family:			Interruptions:	

Adapted from Xie, A., Carayon, P., Kelly, M., Li, Y., Cartmill, R., Wetterneck, T., & Cox, E. D. (2012). *Observation of the FCR checklist training manual.* The University of Wisconsin – Madison, Center for Quality and Productivity Improvement. Retrieved from http://www.hipxchange.org/sites/default/files/FCR/5b-Training%20Manual%20for%20Observation.pdf.

CHAPTER 4

PARENTS' PERSPECTIVES ON FAMILY CENTERED ROUNDS AND THE FAMILY EXPERIENCE

Introduction

Patient- and family-centered care (PFCC) is a complex concept comprised of values and behaviors. The Institute for Patient- and Family-Centered Care (IPFCC) identifies four concepts at the core of PFCC: *respect and dignity*, *collaboration*, *partnership*, and *information sharing* (IPFCC, 2017). The goals of PFCC are to engage families in a collaborative relationship with healthcare professionals in order to provide the best quality of care and outcomes, lower costs, and higher patient satisfaction with health services. Collaboration with parents or families allows a reciprocal sharing of information about the child, the child's needs and preferences, and the medical care options and recommendations. Because parents and families are typically the primary caregivers for children, involving them in their child's care is essential (Mittal, 2014). The American Academy of Pediatrics (AAP) further promoted PFCC with a call for the inclusion of patients and families in bedside rounds as standard practice to share information and engage families' in care decisions (American Academy of Pediatrics Committee on Hospital Care, 2003). Since 2003, family centered rounds (FCR) have become commonplace in many inpatient settings; the AAP continues to support this practice (American Academy of Pediatrics, 2012).

Concurrently, public reporting mechanisms for quality of care and the Centers for Medicare and Medicaid's value-based purchasing plan have led to an increased emphasis on assessing patient satisfaction or the patient experience. Thus, this study will address the understanding of parents' experiences and perspectives of FCR in a hospital setting.

Literature Review

Family centered rounds are intended to be multidisciplinary discussions at the patient's bedside that include the patient and family members to discuss the patient's care and make decisions (Mittal, 2014; Sisterhen, Blazsak, Woods & Smith, 2007). Components of rounds should ideally include patient

and/or family preference for participation, introductions of team members, description of the purpose, summary of the case with relevant test results, discussion of the daily plan and discharge goals with collaborative decisions (Muething, Kotagal, Schoettker, Gonzalez del Rey, & DeWitt (2007). Muething et al. (2007) and Sisterhen et al. (2007) further suggested that FCR provide opportunities for efficient communication via the presence of nurses and other healthcare providers who participate in the exchange of relevant patient information; such enhanced communication may then facilitate more effective coordination of discharge planning (Sisterhen et al., 2007). In addition, FCR should provide opportunities for role modeling by attending physicians regarding effective communication behaviors and interactions with family members and other staff members; and teaching for trainees and well as with families in the presence of real-time patient issues (Muething et al., 2007).

Conceptual models can help operationalize and evaluate quality of care for initiatives such as FCR. Donabedian's model of quality of care embodies three factors of structure, process, and outcomes (Donabedian, 2003). S*tructure* refers to organizational characteristics such as physical facilities and equipment; human resources, training or preparation of providers; and policies and performance expectations, e.g. providing residency training, and workload demands. *Process* refers to the actions or behaviors that employees utilize that are related to patient care including diagnosis, treatment and intervention, rehabilitation, discharge planning, and education of patients and families. The combination of structure and process leads to results or outcomes. *Outcomes* refer to changes in the patient's health status and health-related behaviors, changes in patient and family knowledge, changes in patient and family satisfaction, and other administrative or objective outcomes such as length of stay (LOS) and cost.

When Donabedian's model is applied to FCR, structure encompasses multiple factors such as the composition of the health care team, space, and location for conducting the rounds. The process of FCR may include scheduling of rounds because the schedule affects availability of families and staff, the

frequency and quality of family engagement in the rounds or discussion, and the communication that occurs between families and healthcare providers. Outcomes may include subjective perceptions of patient and family satisfaction with care, patient or family experience, improvement in health status and reduction in symptoms, changes in patient and family education, discharge readiness, and other administrative outcome measures such as LOS, or decrease in adverse events. For purposes of this paper, the remainder of literature review will focus on FCR as related to family and/or patient participation and experience.

Family participation in FCR was valued and viewed as beneficial by families and the majority of healthcare providers in several studies (Abdel-Latif, Boswell, Broom, Smith, & Davis, 2015; Aronson, Yau, Helfaer, & Morrison, 2009; Stickney 2014a). Parents reported overall satisfaction with FCR (Abdel-Latif et al., 2015; Cameron, Schleien, & Morris, 2009; Rappaport, Ketterer, Nilforoshan, & Sharif, 2012). More specifically, satisfaction with FCR was often related to communication and information.

Information exchange was reported as the most or one of the most valuable aspects of FCR by parents and by healthcare providers (Latta et al., 2008; Levin et al 2015.; Lewis et al., 1988; Stickney et al., 2014b). Effective FCR provided opportunities for parents or families to learn more about their child's diagnosis and plan of care (Abdel-Latif et al.; Stickney et al., 2014b; Whelihan, 2015) as well as medications (Benjamin et al. 2015) and long-term expectations (Voos et al., 2011). Kuo et al. (2012) further noted that parents who participated in FCR reported higher satisfaction with receiving consistent information. Rappaport et al. (2012) found only higher satisfaction with parents' knowledge of healthcare team members' roles.

Satisfaction with communication encompassed several elements during FCR. Parent satisfaction was related to opportunities to discuss and contribute to decisions about their child's care (Cameron et al., 2009; Kuo et al. 2012; Ladek et al., 2013) as well as asking questions (Aronson et al, 2009; Abdel-Latif et al., Benjamin et al., 2015; Phipps et al., 2007; & Stickney et al., 2014b). Parents in FCR reported higher

satisfaction with feeling respected and that healthcare providers listened to them (Kuo et al., 2012; Latta et al., 2008). Ladek et al. (2013) observed that FCR provided opportunities for family members to make corrections or contribute missing information to a child's medical record, while Benjamin et al. (2015) reported that the majority of families' questions were answered during FCR. Effective communication for parents and families included the use of lay language and less medical terminology (Kelly et al., 2013; Ladek et al., 2013; Lewis et al., 1988; Phipps et al., 2007). For parents or families with limited English proficiency (LEP), the use of interpreters was vital for effective communication during FCR (Lion et al., 2013; Seltz et al., 2011; Walker-Vischer, Hill, & Mendez, 2015). In addition to communication with parents, parents perceived that FCR facilitated more communication and collaboration between healthcare providers (Latta, Dick, Parry, & Tamura, 2008; Stickney et al., 2014b).

Assessment of the quality of FCR is important to understand FCR's efficacy in meeting healthcare needs and goals of patient- and family-centered care but also to understand the contribution of FCR to the overall hospital experience. Patient experience can demonstrate aspects of patient- and family-centered care from the patient's perspective (Price et al., 2014). Many organizations depend on the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS®) to assess patient experience. The Centers for Medicare and Medicaid (CMS) use HCAHPS® scores to help determine reimbursement formulas in its Pay-for-Performance (P4P) program that was unveiled as part of the Affordable Care Act (Shi & Singh, 2015). In addition to CMS' P4P initiatives, James (2012) reported that 40 private-sector pay-for-performance programs already existed. These P4P initiatives seek to link quality of care, including patient experience, to reimbursement (James, 2012). Haley, Hamadi, Zhao, Xu, and Wang (2017) reported that higher patient experience scores on the HCAHPS® were associated with higher scores in outcome domains, thus the HCAHPS® appears to be an effective tool. The HCAHPS® does indeed include multiple questions that address aspects of patient- and family-centered care such as respect and information or communication, and in 2015 a pediatric version of this survey was

published (CAHPS Child Hospital Survey, 2017). However, the HCAHPS® does not specifically address FCR. Thus, alternative methods must be utilized to obtain specific feedback about patients' or parents' experiences with FCR. Price et al. (2014) recommended the use of narrative feedback from patients or consumers to help explain patient experience data and to more fully understand factors that may not be explicitly included in standardized questionnaires or rating scales. This study seeks to understand parents' perspectives about FCR and how FCR impact parents' experiences in the hospital setting.

Methods

The study was approved by the Institutional Review Board at the medical center. Support from nurse managers was obtained for the project, and access to medical teams was facilitated by two physicians who supported the project.

Study Design

A qualitative exploratory study was conducted to understand parents' perspectives and experiences with FCR.

Setting

This study was conducted at an urban academic medical center that includes a 205-bed children's hospital. The study occurred on four 20-bed general medical units, for a total of 80 beds. These units included infants and toddlers, school-aged and burn care, adolescents, and a general medical unit that includes a pediatric clinical research unit.

Participants

Parents were eligible for the study if they had participated in FCR that day, were fluent in English, and their child had been in the hospital at least one day. The primary researcher did not awaken parents if they were observed to be napping after rounds. Parents were excluded from an invitation to the study if their child was being imminently discharged after FCR, due to activities and care related to discharge. In addition, because of the primary researcher's relationship with cardiology services, parents

whose children were followed by cardiology were excluded. Other exclusion factors included the acuity of patients or safety issues. For example, a few patients were imminently scheduled for procedures or tests; a few patients needed medical attention due to acute symptoms; and a few patients had security guards sitting outside their doors due to safety issues.

Data Collection

The primary researcher (DWB) observed family centered rounds with general pediatrics teams and a pediatric subspecialty team; observations provided contextual information about the FCR experience. After each daily rounding session, the primary researcher personally invited parents to participate in a semi-structured interview. Semi-structured interviews obtained parents' feedback about FCR, specifically aspects of FCR that contributed to their overall hospital experience and their perceptions about the practice of FCR. Semi-structured interviews allowed the researcher to acquire specific information about a topic or category (Fetterman, 2010) while allowing flexibility to respond to or probe participants' answers for new ideas if they emerged (Merriam & Tisdell, 2016). Questions for the semi-structured interviews were developed based on published literature, the primary concepts of patient- and family- centered care, and with feedback from the Pediatric Family Advisory Council at the children's hospital; the advisory council included hospital staff members as well as parent volunteers. Questions for the semi-structured interviews are listed in Appendix 4.A.

Interviews were conducted on the same day that the family member had participated in FCR, which allowed for effective and accurate recall of the FCR experience. Prior to the invitation, the primary researcher confirmed with nursing staff that respective patients remained stable and that interviews would not interfere with any scheduled patient care. Parents, who agreed to participate in interviews, reviewed and signed informed consent documents. Interviews were audio-recorded with parents' permission, or written notes were documented during interviews. The majority of interviews occurred in the patients' rooms so that parents did not have to leave their child's bedside. Audio-recorded

interviews were transcribed, and written notes were typed into a narrative transcript. Audio files were stored on a secure cloud server at the medical center, and written interview notes and transcripts were locked in a filing cabinet in a locked office at the medical center. Transcripts and other written notes from interviews were anonymous and were assigned a numerical code that corresponded with the FCR encounter; no patient or parent names were included in these documents, and other identifying patient information was excluded from transcripts. All parents who completed an interview were provided with a $10 gift card.

Demographic information about the parents was not collected. However, demographic data and intended discharge disposition was obtained from the electronic medical record for each child whose parents participated in interviews. This data provided contextual information about the children whose care was discussed.

Data Analysis

The primary researcher (DWB) discussed interviews with a second researcher (PD) on a weekly basis to discuss initial impressions. DWB and PD independently read through the transcripts to become familiar with content, and DWB coded the written transcripts with HyperRESEARCH version 3.7.5. HyperRESEARCH allowed the researcher to apply codes related to patient- and family-centered care as well as codes that emerged while reading the transcripts. Codes were reviewed and analyzed using content analysis to determine overarching themes. Overarching themes were reviewed for congruity and agreement between two researchers (DWB & PD). For purposes of this manuscript, transcripts were renumbered with random numbers, and parents' quotes were slightly edited for readability, e.g. adding words to form complete sentences and omitting filler speech.

Results

Seven parents declined to participate for various reasons including comments that they had nothing to add or concerns about privacy due to the legal language in the informed consent document.

Other parents declined or were unable to participate because they were tending to their children, were working on their laptops, or wanted their spouse to be present although the spouse had not participated in FCR that day. Another parent had been engaged in a highly confrontational discussion with the medical team during FCR, and although she expressed appreciation for the opportunity to participate, she declined because she remained too emotionally distressed and focused on her child's needs.

Twenty-eight semi-structured interviews were completed with 31 parents, including 25 mothers and six fathers. Three of the interviews were conducted with both mother and father together. Of the interviews, 21 were audio recorded and seven were hand-written. The length of audio recorded interviews ranged from 8.7 minutes to 34.7 minutes with an average length of 20.1 minutes, 95% CI [17.2, 23.0]. Time was not measured for non-recorded interviews, but these interviews are estimated to have ranged from 20-25 minutes. Eight (29%) of the interviews represented patients from the general pediatrics team A, eleven (39%) represented patients from the general pediatrics team B, and nine (32%) represented patients from the pulmonary subspecialty team.

Demographic information about the participants' children is displayed in Table 4.1. Because one parent had two children hospitalized concurrently, 29 children are represented. Ages ranged from six weeks to 18 years old. Length of stay at the time of interview ranged from 1 – 156 days with a median LOS of 3 days, 95% CI [2, 4]. Examples of primary diagnoses of the children included cystic fibrosis exacerbation, respiratory syncytial virus, upper respiratory infection, bronchiolitis, failure to thrive, Trisomy 21, metabolic or genetic disorders, influenza, meningitis, hypoxia, gastroenteritis, chronic lung disease, infantile fever, and severe eczema.

Table 4.1. Description of Children Whose Parents Completed Interviews (n=29)

Sex	
Female	16 (55%)
Male	13 (45%)
Age (years)	
Median with 95% CI	2.0 (1.2, 6.3)
Mean with 95% CI	4.2 (2.5, 6.1)
Race/Ethnicity	
African American	12 (41.4%)
White/Caucasian	13 (44.8%)
Hispanic	1 (3.4%)
Other	3 (10.3%)

Qualitative themes from interviews demonstrated six primary or overarching themes that reflect parents' perspectives and experiences with FCR.

FCR support shared decision-making with parents.

Parents reported positive experiences with FCR when their input, and/or their child's input, was included and respected. Most parents indicated a high degree of satisfaction with FCR, citing the ability to share input as well as have their questions answered. Parents' believe their input and questions are valued and considered in decisions. An example of this came from one mother who stated,

> *They asked if I had questions…. They did make me feel comfortable with wanting to ask questions…. As a parent, of course I would definitely want to be part of the decision of her care. I definitely want to know what is going on with her…. They are very concerned and …overall, that really helps out as the parent…to let me know what is going on with her as well and allow me the opportunity to show my concerns, if I had any. They give me the opportunity to bring that out.* (interview one, mother of a 6-year-old child).

Yet another mother summed up the value of participating in FCR with this quote,

> *They made me feel comfortable…. They were pretty respectful of me and my knowledge of him [the child]….They didn't just talk around me or about him, they actually included me…I think that I was part of the decision making…. It makes me, as a parent, feel like I'm not being kept out of the loop…. they are making me feel like I'm being a part of his care.* (interview 28, mother of a 7-month old child)

Several parents expressed feelings of respect and the ability to share different ideas during FCR. One mother remarked "*I'm a mom of a chronic kid – they value what I have to say. They work hard to listen to us….how I felt about the plan, they honored my disagreement with the plan – it's huge that they respect that*" (interview 13, mother of a 6-year-old child). Another mother shared this comment that the team frequently, "*Ask[ed] me how I feel about their plan*

and if there is an alternative that I think they might be able to do" (interview two, mother of a 20-month old child). Another mother whose child had chronic and complex medical issues remarked on the importance of resolving issues with this quote,

> *They did listen when I expressed concerns beyond follow up…the big picture challenge for us with discharge…. It's helpful for me as a parent to hear physicians' priorities, but including the parents and how they think it will work. I get to voice my concerns and issues.* (interview seven, mother of an 8-year-old child)

Parents also believe their child's input and participation in FCR is important. Examples of this came from a mother whose child has a chronic medical condition,

> *They definitely get my input. Generally, too, [child's name] puts a lot of input, too….and I appreciate that they listen to her and not just ask me the questions, because she definitely will answer the questions for herself…which I think is a big thing.* (interview 23 mother of a 7-year-old child)

A similar opinion was voiced by another mother, *"I think that's great because she's old enough to understand what's going on, and I think that it makes her feel like she has a voice in this and has a say. I think it's good that they include her"* (interview 14, mother of a 13-year-old child).

Alternatively, parents expressed displeasure when they were excluded from part of rounds. One mother noted that rounds had started in the hallway without her and remarked,

> *"I wish they would knock on the door and let me know they are going to come in before they do their hallway huddle…. I like to be involved, and I understand their reasons to get a plan together [in the hallway], but they could come inside and do that discussion in the room. I want to be involved. If there's a debate, I want to give my two cents or ask questions.* (interview nine, mother of a 2-year-old child)

These quotes demonstrate parents' strong beliefs in participating in FCR, but also show that they believe their children should be involved when possible.

Parents also view themselves as advocates for their children during FCR. While parents often viewed their input at being valued and respected during FCR, they also expressed the role of being an advocate for their child during FCR. One parent who did not think he was supposed to participate in FCR declared, *"This child can't speak….They never take that into consideration – this child is not able to speak so her parent is speaking. Listen to that voice.*" (interview 25, father of a 15-year-old child). One mother of a child with a chronic illness stated*,*

> *I tend to be an advocate and seek answers. If I wasn't here and if the team didn't ask…. I've had eight years of this…. We are the ones who know her best; we have to be able to take her home. They are more educated, but we know her…We never leave her – she can't call for the nurse. I know her different cries and sounds and what they mean – her facial expressions. We understand her communication better.* (interview seven, mother of an 8-year-old child)

Other parents shared similar sentiments of advocating for their children, especially if they had more experience with caring for a child with chronic conditions.

FCR provide opportunities for information sharing and effective communication with everyone involved in a child's care.

Information was frequently cited as the most important, or one of the most important, aspects of FCR for parents. Parents craved information about their child's diagnosis, current status, pending tests or procedures, expected recovery, and discharge. One mother was very satisfied with the information she received as she remarked, "*when your son has been in the hospital so many times…. I learned one new thing yesterday [in FCR], which was really helpful*" (interview 17, mother of a 7-year-old child). Another mother commented that, "*they answered every question I asked, and it was good. I*

understand more about my daughter's situation…what's happening, the action plan, what she has, and everything" (interview three, mother of a 6-week-old child). Information about the daily plan was also important for parents who wanted or needed to help prepare their children for procedures. One parent who had two children in the hospital stated,

> *I guess the information was the most helpful part. Letting us know what's going to happen throughout the day…..so we can anticipate things a little easier. Usually after we know what's happening, we usually talk to them [children] about it…we let them know what's coming, too, so it's not a shock. I think it's really helpful.* (interview 15, mother of a 22-month-old child and a 3-year old child)

Information was cited as essential for first-time parents and also for caring for their children after discharge. One mother commented on both of these issues when she said,

> *I just want to make sure that I am prepared for her to come home. I need to make sure that I know what I'm doing once she comes home because I don't want her to come back and me not knowing what I'm doing…. I'm a first-time mom…. I don't know what is normal and what is not normal, because she's not a normal baby.* (interview 16, mother of a 5-month-old child)

A mother who was learning to manage a chronic illness summed up the value of information during FCR,

> *It's important for me to learn so I know what to do when we're not here…when we're at home. That makes a big impact because when we're in our day to day life, we don't realize we could be doing things that could actually trigger [the illness]…I don't want to go home…with no knowledge - still doing the same things and we're back here again with the same exact problem….I learned something today - I can take that with me…. That made me love it [FCR]….They want to know what they can do to help us outside of the hospital. And that's very important to me and a lot of parents. As parents, we don't*

know everything. And the fact that you give us the information…[it's] so much more helpful. (interview one, mother of a 6-year-old child)

As part of information, parents appreciated when healthcare providers explained things in terms they could understand and when communication was adjusted based on parents' experiences. One mother who has a healthcare background stated, "*I want the jargon because I process better as a [professional]. They start out with the jargon, but then they bring it up to my level as they respond to my need and my knowledge*" (interview 13, mother of a 6-year-old child). A father of a child with a chronic condition also desired more specific information because of his experience with his child.

…We're truly number conscious with lab values and stuff like that…. Pull labs up and print a copy so we can look at trends to get an idea of where we're at, what's going on…If we ask for it, they'll provide that information to us. We look at it, we trend it. (interview ten, father of an 18-year-old).

Alternatively, one mother described the challenges and importance of sharing information during FCR,

My biggest thing is making it so we understand what they're saying, because they talk fast. Everybody they're doing rounds with understands what they're saying, but I don't [understand] the scientific part of it…. I ask if I don't understand it, and they'll explain it to us…When Dr. [name] was showing the CT scans…, she was explaining it to me and answering all my questions…. I was over there looking at the [computer] screen, too. (interview 23, mother of a 7-year-old child)

Similarly, a father appreciated when healthcare teams discussed things in simpler language, so he could stay involved in the discussions.

…as soon as they were done having their conversation, which means something to them, they would bring it down to our level and say, "okay, this is what this means." They were

very good about that. I didn't feel like I was being left out of the loop or being talked to above my head. (interview four, father of a 3-year-old child)

Parents clearly want information about their child so that they can provide good care, but they may also need healthcare teams to adjust the presentation to parents' level of understanding and experience. In addition to sharing of information, almost all parents recognized the value of FCR for healthcare providers to share ideas, as well as to receive and exchange information about a child and the plan of care. Having the team "on the same page" was a phrase echoed by multiple parents, and one mother commented,

I like it [FCR] because it's different views and you get a lot of different components…all that in one room. You get a lot of people that have their hands in the situation all together instead of having them come one by one. They are all in one accord…and they know what the goal is for the day and how to proceed…It's not miscommunication because everybody is here. (interview 22, mother of a 4-month-old child)

Similarly, another mother recognized the potential for mixed communication without FCR, and she made this statement,

It's nice to see that everybody is informed and…on the same page. I think that if it was just a few people, you know you go back to that game when you were a kid, ''telephone." Sometimes as the information goes down the line, it gets more convoluted and the correct information can't get transferred back. I think with everybody being on that same page, it really makes me feel comfortable. (interview four, mother of a 3-year-old child)

As part of the communication process during FCR, the use of dry erase boards, also called white boards, was raised by several parents. Parents reported that using these helped them remember their questions for FCR.

We started using the big whiteboard to keep notes and write questions and stuff to help remember them in the future. If my wife can't be here [during FCR] or if I can't be here, we can leave it up there for them to either read themselves or for me to remember to ask them whenever they get here…. It's been fantastic because I can also write down the responses that I might not remember.... The questions are right there, and they can all see the questions and all of them can address it [in FCR]. (interview 20, father of a 15-month-old child)

Similarly, the white board was useful when parents could not be with their child all day and for sharing helpful information for everyone involved. One mother explained, "*The whiteboard [is] helpful to use to give tips for us about feeding and for the nurses…and we can add our phone # to the whiteboard for nurses"* (interview 18, mother of a 4-month-old child).

Several parents commented that communication would be even better with more frequent updates than only the morning FCR. Evenings and weekends were specifically highlighted as opportunities to ensure good communication. One mother noted weekends as being different, "*The weekend team is a little bit different than the weekday team…. Communication sometimes breaks down and I can understand that in a hospital, they get busy….The weekend team consisted of two doctors, whereas the rounds yesterday was everybody….*" (interview twelve, mother of an 8-year-old child). A father who had frequent inpatient visits with his child realized advantages of updates in the evenings.

I don't know if it would be beneficial to do an evening [FCR]. Even if it's not as in depth but just a " lab [report], … activity, [and] this is what we anticipate overnight." Day shift going to night shift has to do something [updates], so… why not do it here so that if family is here, the patient is here, they have involvement in that and can help either quantify some of those goals or discount some of those goals Instead of waiting until the

morning….That's a lost opportunity possibly by not doing that evening round, update, mini-round, whatever you want to call it. (interview ten, father of an 18-year old)

Similarly, a mother and father noted the value of having more frequent updates for them and for the team to monitor changes in their child's status. Their exchange highlighted their opinions.

Father: *…It would be great to have one in the morning and one in the afternoon or in the evening….to be here 8 AM when they got here and then not talking to the whole team until 8 AM the following morning…. a lot can change in that amount of time….to me the team would benefit from it, it's just doubling the same exposure that they're getting. We would just get double confidence….*

Mother:*… it doesn't necessarily have to be the whole team, just maybe a few of them.* (interview four, parents of a 3-year-old child)

These quotes from parents demonstrate that FCR may facilitate more effective information exchange between parents and healthcare providers as well as between multiple healthcare providers.

Of note, when children were treated by multiple medical teams or specialties, parents expressed a preference or expectation for physicians to participate together in rounds for better communication and coordination of care. One father noted a difference at this hospital when specialists conducted rounds collaboratively, *"……the format here, where everybody is together, I think helps a lot and keeps things from falling through the cracks as well*" (interview ten, father of an 18-year-old child). Another mother noted,

It's better because you get all of the information at one time instead of one doctor coming in, then the endocrinology team coming behind the regular pediatrician. You get all of the information and any questions that you have answered at one time….They

come together and give the plan of how everything is going to be worked out. (interview 28, mother of a 7-month old)

Similarly, another mother commented that her children had multiple issues and "*we need a team of doctors in different areas to give us the run down. I think I like that better than just one doctor coming in*" (interview 15, mother of a 22-month-old and a 3-year old).

When children's subspecialists were not involved in FCR, parents expressed concerns with the potential for missed communication or difficulty in coordinating care. Examples of this came from these parents,

…during that time [FCR], if we're making a plan for the day…rather than the doctor wasting time and going back and communicating [with the subspecialist]….that the specialist be there, too, so that they can hear everything all at one time….that would be very helpful. (interview 19, mother of a 13-month old child)

Another mother whose child received services expressed a desire for specialists to conduct rounds together and expressed her frustration with different information from multiple specialists,

It's really irritating. They are a team, working with one child. I feel like they should all be able to communicate with each other without a problem…. Neuro tells me one thing, pediatrics tells me another thing…. The teams don't communicate…..I feel like they should have a person from each team be here [during FCR] so everyone can understand. I can get the answer to the questions that I need. Because when I ask the doctors about neuro or infectious disease, they're like "we don't know, we have to contact that team." And I feel like that's a problem sometimes. (interview 16, mother of a 5-month-old child)

Miscommunication was also noted by another mother whose child was treated by multiple specialists who did not conduct rounds together; this mother remarked that she received *"mixed messages*

yesterday – one person would come in and then negate the other person who came in" (interview seven, mother of an 8-year old).

Only a few parents commented that they preferred separate rounds from specialists. An example from a mother was, "*Separate specialty rounds is better because it's less information all at once. I know they consult with each other and are cohesive*" (interview nine, mother of a 2-year-old child). This parent's response was less common than most parents', but it demonstrates that parents may have different preferences regarding participation by different specialists. Overall, quotes demonstrate that regardless of personal preferences, communication between specialists was desired and expected.

Parents value the presence of their child's bedside nurse during FCR.

When parents were asked what other healthcare professionals they would like to see on the rounding team, many parents commented on the importance of their child's nurse because they viewed nurses as the most knowledgeable about their child's status. One mother commented that she wanted to see, "*our nurse…. She sees him the most and sees how he's doing and she's the one that updates the doctor with whether he's breathing faster, or that kind of thing"* (interview five, mother of a 6-week-old child). Other comments included, "*I think maybe his nurse would be good….she knows him best of the medical providers. The nurse is with him 24/7*" (interview 27, mother of a 2-year old child). Parents also desired nurses' input for decisions and for firsthand knowledge of care plans. One mother wanted "*…the bedside nurse to be part of the discussion and hear all the details, plans and decisions versus just reading the orders*" (interview 13, mother of a 6-year old).

Several parents also valued the nurse's presence to support families during FCR as evidenced by this quote,

> *I am aware the bedside nurse was not in rounds [today] and it was another nurse. But the bedside nurse was there other times…. The bedside nurse is optimal because she*

knows the day to day things, the bedside activities and what happened…or if the family has specific questions. (interview seven, mother of an 8-year-old child)

Nurses were also valued to help ensure that parents' input was heard and validated; one father commented,

Having the nurse here helps because the nurse is the one that's checking on him during that 12-hour period of time. So that's always nice to have the person that has been the most familiar with him in here to have back up to whatever statement we would make so it doesn't look like we're just saying things like "he's been doing this." Whenever the nurse is there to back up your statements, that helps. (interview 20, father of a 15-month-old child)

These quotes from parents indicate that a child's bedside nurse is an important member of the FCR discussions for several reasons including family support but also input about a child's status and care.

Parents had mixed opinions about the composition of the rounding team during FCR.

Most parents expressed satisfaction with the composition of the FCR team. Other parents noted specific providers involved in their child's care whom they would have preferred to see during FCR. Examples of these providers were, "*respiratory therapy – I think that would be good… she's coming in daily to make sure that his respirations are what they need to be…and working with us to help him*…."(interview five, mother and father of a 6-week old child). Child life, speech therapy and physical therapy were also mentioned by several parents; parents were mainly concerned that these other healthcare providers be engaged in effective communication with the rest of the team, i.e. "*I think it's okay [that physical therapy is not in FCR] as long as everything is communicated*" (interview twelve, mother of an 8-year-old child). Another mother commented that she was "*not sure if the team listens to OT [occupational therapy] about feeding – they [OT] gave us good tips, and I hope the team listens to that, especially if they make feeding decisions for him*" (interview 18, mother of a 4-month-old child).

Other parents expressed concern that some team members were not necessary during FCR. One father expressed, "*I do not know that they are contributing in any way in her treatment plan. So if they are not, I don't think that they should be part of the discussion*" (interview 25, father of a 15-year-old child). Another mother explicitly stated, "*I can discount half the people there because they are not the primary people in my daughter's care. I care about the attending, the pharmacist, and the fellow or senior resident*" (interview 13, mother of a 6-year old child).

Several parents expressed dissatisfaction if an attending physician was not explicitly identified during FCR. "*I don't know if there is an attending or fellow. It should be clear who the leader is*" (interview nine, mother of a 2-year old child) or, "*it seems…that they are not sure themselves yet. I didn't understand who was in charge of making the decisions….Who is in charge here? I like to always know who is the one making the decisions, and I did not know*" (interview 25, father of a 15-year old child). One mother recognized the value of the attending so that communication would be more effective, "*For me, there is nothing worse than somebody is like, 'I'll have to look into that…' and somebody from the group not knowing. With the attending physician there, I feel like everybody's questions can be fully answered at that moment"* (interview four, mother of a 3-year-old child).

Parents' responses demonstrate that although they have different needs and interests regarding healthcare providers' participation in FCR, communication between providers was expected and essential.

Parents need orientation to and information about FCR so that they are prepared to participate.

Some parents were aware of FCR due to prior hospitalizations or from longer LOS that allowed them opportunities to experience the hospital's daily routines. One father commented, "*I think having been around for a while with both kids…with numerous stays, we're sort of used to it (FCR*)" (interview 10, father of an 18-year-old child). When parents were informed ahead of time, they had positive experiences as noted by these examples.

*Actually, last night I was told by a nurse that in the morning the doctors can come through pretty early….That was really good because it actually had me prepared for them coming…especially waking up in the morning, you're not really too big on a bunch of people rushing in at once….(*interview one, mother of a 6-year-old child).

Another father noted the importance of knowing about FCR in advance for the sake of his child's privacy when he stated, *"…so giving us a little bit of prep time, in case we had to cover her up*" (interview four, father of a 3-year-old child).

However, most parents expressed lack of awareness of rounds and indicated a preference to have information in advance about rounds. Parents were frequently awakened and expressed almost a sense of surprise that FCR were beginning. Comments from a mother and father together noted,

All of a sudden we were awakened, and here's all these people…I appreciate that they let us sleep as much as we could and then woke us up for it, …but I think maybe a heads up or what to expect….so that you can plan around the daily activities….because if we had just slept through it…I don't know if I would have known any different, like was I supposed to be included? (interview five, parents of a 6-week-old child)

Some parents also did not understand the purpose of FCR; some parents thought FCR were only for the purpose of education and not for family participation. One mother said,

When I have the whole team, it's like they have a class or something….They are coming for other people, for the students, not for me. I didn't feel comfortable asking questions I'm not sure if… I understand why they are here….I don't know the purpose, I don't know anything. (interview three, mother of a 6-week old child)

Another mother had a similar statement.

I just wished that I would have known that it was happening or what was going on before. I was like, "rounds? what are rounds? I don't know what this is." …My son has

been here before… and the rounds thing is new. (interview 24, mother of an 8-year-old child)

Parents who stayed overnight at the hospital discussed the importance of knowing about FCR so that they could manage their own sleep and self-care and still participate in FCR. Two different mothers commented that they would have "*put a bra on*" before FCR (interview 23, mother of a 7-year old and interview 11, mother of a 2-year-old child), and one of those mothers added that had she known about FCR in advance, she "*would have time to get awake, freshen up….Not everyone wakes up early….Our schedules are off. I haven't even washed my face, brushed my teeth – [I] need to be aware and awake*" (interview 11, mother of a 2-year old child). Self-care and hygiene was noted by another mother who stated,

I just got out of the shower,… so what if I was in the shower [when they came for FCR]? I'm glad I got up,…I was wondering, "should I get up now, or should I wait?" …So, it was a good thing I was up early. (interview 19, mother of a 13-month old child)

Other parents waited to get breakfast so that they would not miss FCR. A mother commented,

I've never experienced rounds before so this is something new and I actually like it, I wait for it….I don't get to get breakfast, I make sure I'm around for when it [FCR] happens. After rounds I'll probably go get something to eat…. (interview 22, mother of a 4-month-old child)

Some parents who did not stay overnight at the hospital also expressed a desire to have an approximate schedule for FCR so they could plan their travel times and other logistics in time to participate in FCR. One mother commented, "*I am a working mom….I know I will miss some rounds, and I live over an hour away, and I left today at 4:45 AM to be here in time to do some feedings and rounds, but I have to go to work*" (interview 18, mother of a 4-month-old child). Another mother, who commuted to the hospital daily and desired to participate in FCR noted that,

…maybe they could ask me "what time will you usually be here? We can meet you." I don't want to give them any inconvenience because I understand their schedules…but if they could give me a time frame, that would give me a little bit of convenience which would be great….I know one time I missed them. I saw them rounding and I thought they didn't see my son yet, but apparently they saw him first…. Both of us [my husband]…we were waiting for them to come in and we finally asked a nurse…and the nurse said they already came. (interview 27, mother of a 2-year-old child)

One mother wanted to be prepared for FCR discussions, especially related to safety.

They never tell you the time. That could be changed so a person can be more aware. If I'm not all the way awake, I might fall asleep. It might not be safe – I may give the wrong answers to questions… about her medication. I may not fully understand what they say. If I knew the night before or even a half hour, I would have time to get awake….

(interview eleven, mother of a 2-year-old child)

These quotes from parents demonstrate the challenges they face with managing their own daily needs but wanting to be available and ready to participate in FCR.

In addition, parents desired information about the structure of rounds, e.g. expected team size, and the purpose of FCR. Parents also expressed their perceptions that larger team sizes tended to be intimidating and concerning for parents. Although most parents were comfortable with the size of the team, some expressed concerns. One mother responded that the team was,

too large…If they know how many people are going to be on the team and ask me if I want all the team to come in, or if I can go to the door….or maybe [have] less people to be part of it…[They need to] do a better job of letting parents know the size of the team and giving [them] choices. (interview eight, mother of a 20-month old child)

Another mother commented that she found the team size to be "*a little overwhelming because of the number of people on the team. It was more people than I expected*" (interview seven, mother of an 8-year-old child). One mother recognized the benefits of having a large team despite her discomfort; she stated,

> *….Sometimes it can be overwhelming because of the number of people. Some people [parents] get nervous when there are a bunch of people and everyone is staring at you, so it's overwhelming.…but at the end of the day, the more people around, the more I learn.* (interview 17, mother of a 7-year-old child)

Yet another father expressed concern over the large team size and their purpose in FCR discussions.

> *The first time was just a little nerve wracking as you had a large consortium of doctors coming in…and we didn't know what the heck was going on… and they are there to help. It took a second for me to get that to register, because normally whenever large groups of people show up to discuss whatever you're doing, it seems like it's always for bad reasons, not for good reasons.* (interview 20, father of a 15-month-old child)

These quotes from parents indicate that some parents may prefer smaller teams during FCR or information about the team size and purpose of FCR ahead of time.

Provider behavior affects parents' perceptions of respect and care.

Parents commented on various actions from healthcare providers that they found to be helpful during FCR, both verbal and non-verbal communication. Many parents reported that the healthcare teams listened to them during FCR. This was exemplified by these quotes, "*They ask me how I think she is doing because I know her best.…They listen – that shows enough. They really listen.…By the way they look at me, the things they ask me afterwards. They seem engaged.…*" (interview nine, mother of a 2-year old). Other examples were noted as, "*She referred to our son as [name], not just as our x-week old.… She humanized him ….Now he is a person and not just a 6-week old male…or even referring to us*

by name" (interview five, father of a 6-week old). A father shared his thoughts about interactions with employees along with his appreciation for being included as an equal parent with his wife, especially when he compared to a different hospital. He described his experience,

> *…at a different hospital,…I felt like just an entity in the room that didn't even need to be there. And I didn't get that here…. They're treating us both as equals….not deferring to mom…. Bedside manner is important to us, because I don't want to be treated like a number, I don't want to be treated like a job…. I would rather have someone who is going to walk in, know her name before they come in, know our names, and just establish that kind of relationship. And I feel like the bedside manner here is what keeps us coming back. For the most part, every person we've come into contact with has been nicer than the last. And that is very, very important to establish that we have a good experience here.* (interview four, father of a 3-year old).

Some parents included non-verbal communication in their comments about respectful provider behavior. One mother noted, "*They always ask me if I have questions. They look at me in the eye when they're talking….They knock before they come in….They ask me if I'm doing okay, if [child's name] is doing okay*" (interview six, mother of a 6-month-old).

In addition to communication with parents, healthcare providers' interactions with patients was also recognized by parents as being helpful and important for their children.

> *Everybody came in with a smile, said good morning, or good evening….Making my daughter feel comfortable, letting her know that they are there for her…that's the key….As the parent, watching how they interact with her and how she was interacting back to them and happy and laughing with them, and they tried to do things to make her laugh. They make her feel comfortable as a patient here.* (interview one, mother of a 6-year old)

Another mother commented that,

> *…it's nice that somebody breaks away and is talking to her. I know when they came in, he [doctor] came in and was checking her and talking to her and asked her who her stuffed animals were, so it was kind of nice…and I think it made her feel a little bit more comfortable.* (interview four, mother of a 3-year-old child)

Provider behavior clearly made an impact on parents and patients, even seemingly small acts that sought to engage patients and parents on a personal level.

Personal interactions extended to introductions by the various team members, which many parents viewed as an element of respect during FCR. When parents were specifically asked about healthcare team introductions during FCR, most parents appreciated such introductions. "*It's nice that everybody introduces themselves, and it makes a bad situation just a little bit more comfortable*" (interview four, mother of a 3-year-old child). Parents also appreciated having a printed paper with photos and names of medical team members, "*I've got a piece of paper with all of their pictures on it and their names and the type of doctors they are…. It was very convenient"* (interview two, mother of a 20-month old). Several mothers commented on the need for repetition to help them remember names as seen in these remarks, "*I remember faces better than I do names….So it's probably going to take me a couple of times to actually remember everybody*" (interview twelve, mother of an 8-year-old child), and *"There are so many of them…Some of them were familiar faces but…I've met so many doctors and so many people that I just don't remember names…*." (interview 16, mother of a 5-month-old child). Respect was identified by yet another mother's comment, "*They didn't do it [introduce themselves] today, but they should do it every time out of respect. Other teams do this – maybe it depends on the doctors. It should be mandatory – to know who is involved*" (interview eleven, mother of a 2-year-old child). These comments demonstrate the value of more consistent introductions, personal interactions, and other provider behavior during FCR.

Discussion

This study clearly identified and explained parents' perspectives on FCR as practiced in this hospital setting. Parents' opinions and input identified positive experiences with FCR in this hospital, but such feedback also revealed suggestions for improving parents' experiences with FCR. Parents' feedback about FCR indicated an overall satisfaction with FCR. This is consistent with the literature. Furthermore, parents' perspectives about FCR show that FCR generally support concepts of patient- and family-centered care, particularly dignity and respect, participation, and information sharing. The hospital's culture and values of FCR appeared to welcome parent or family engagement in FCR along with an openness to questions from families. Family centered rounds clearly facilitated participation by parents and occasionally by patients. Discussions and decisions about care were cited frequently by parents who often felt included in dialogue with the healthcare teams during FCR.

Parents definitely believed that FCR provided them with essential information and parent education about their child's care, including management of chronic conditions. Parents are typically the primary caregivers at home, and thus they need to safely and effectively care for their children after discharge in order to manage symptoms, any necessary medications or interventions at home, and to help prevent readmission. Healthcare providers may need to adjust how they communicate information with parents based on parents' experiences; parents of children with chronic conditions may have more knowledge and familiarity with medical terminology than parents of newly diagnosed children. Similarly, first time parents or parents of newly diagnosed children may need additional information as they prepare for new responsibilities. Alternatively, recognizing that some parents' have professional healthcare experience may allow for more use of medical terminology. Parents also viewed FCR as an opportunity to facilitate better communication and exchange of information between parents and healthcare providers as well as between multiple healthcare providers despite the inconsistent

subspecialist communication. Communication between providers was reported by parents as essential to help maintain continuity of care (Miller et al., 2009).

Dignity and respect were demonstrated by healthcare teams who recognized parents' experiences and knowledge of their children, especially children with chronic conditions. Parents' advocacy for their children appeared to be related to their experience of caring for children with chronic conditions and/or the vulnerability of children who were non-verbal and unable to speak for themselves. Providers' behavior related to interpersonal interaction and non-verbal communication also represented dignity and respect towards parents and their children during FCR.

Parents' feedback about structural elements of FCR provides insight regarding strengths and possible weaknesses. Parents clearly preferred their child's bedside nurse to be present during FCR, which is highlighted in prior studies (Carayon et al., 2014; Latta et al., 2008; Seltz et al., 2011; & Walker-Vischer et al., 2015). Because nurses spend more time with patients and parents, parents may feel higher levels of trust with their children's nurses and may have established stronger relationships or connections with their children's nurses. Parents were less satisfied with some structural elements of FCR such as team size. This is consistent with studies by Beck, Meyer, Kind, & Bhansali (2015), Carayon et al. (2014) and Xie et al. (2015). Parents may prefer to decide whether to participate in FCR based on team size if that information is available in advance.

Despite high levels of satisfaction with participation in FCR, parents' feedback indicated a need to improve their awareness of and preparation for FCR. This was most noted in parents' desire to know the approximate schedule of FCR as well as the purpose and expectations of FCR so that they could manage sleep and self-care. Parents' desires to be awake, dressed and ready for FCR also reflect their desire for personal dignity and respect when interacting with healthcare providers.

Although parents noted the enhanced communication during FCR, there were clearly opportunities to improve information sharing from parents' perspectives. While parents had mixed

opinions regarding the presence of additional team members such as therapy services in FCR, parents clearly indicated that communication with such additional team members was important. Of note was parents' mixed experiences regarding subspecialist communication and the impact of this on information sharing. While it is not practical for all subspecialty teams to participate concurrently in FCR, strategies to facilitate communication between subspecialists may improve parents' experience with information sharing and thus their overall experience with care. In addition, a few parents indicated that more frequent and timely updates might improve their experiences with information sharing and communication with various healthcare providers. Additional information desired by parents was daily introductions of healthcare team members; parents encounter multiple healthcare providers during hospitalizations and may not remember names of so many new people in a short and stressful time period.

Study Limitations

This study presents with several limitations. Not all parents who participated in FCR were interviewed, and parents who did not participate in FCR were not interviewed. It would be helpful to know why some parents chose not to participate in FCR when given the option. Similarly, while parents who were not available for FCR could not have commented on the FCR, their feedback may have provided a valuable comparison sample for parents' overall experiences, especially related to general concepts of patient- and family-centered care. In addition, parents who participated in this study generally had positive experiences with rounds. Thus, the feedback from interviews does not reflect alternative views of parents who did not participate or did not have positive experiences. This study excluded parents with limited English proficiency; the perspectives of parents with limited English proficiency may be valuable regarding communication and cultural values with their children's care. Results may not be generalized to all parents' experiences. Interviews were only conducted on general medical surgical units and represented general pediatrics and only one subspecialty service. Because

feedback was not obtained from parents with children on specialty units or with other subspecialty services, results may not be fully applicable to other specialty units or subspecialty teams.

While qualitative interviews allow researchers to probe and describe experiences with a richer level of detail, anonymous questionnaires or rating scales about FCR may have captured a larger audience and resulted in responses about experiences from a broader array of parents. Future research could explore or develop a standardized questionnaire about parents' experiences with FCR or may consider other strategies to collect a wider array of parent or patient feedback about FCR. In addition, exploring the relationship between parent satisfaction or experience and clinical or administrative outcomes may further the understanding of the value of FCR in children's inpatient care.

Conclusion

This study provides feedback about parents' experiences with FCR, namely that FCR support family participation, information sharing, and dignity and respect during the care of hospitalized children. Information was often the most valuable aspect of FCR from parents' perspectives. Nurses were identified as valuable healthcare team members during FCR, and parents also identified a preference for subspecialists during FCR to enhance communication and information exchange. Several strategies to improve experiences with FCR were highlighted by parents, most notably better information about the purpose and scheduling of FCR so that they could fully participate. This and other suggestions warrant consideration for further development and practice of FCR. Such improvements may contribute to higher parent satisfaction with their child's hospital experience.

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Appendix 4.A

Semi-structured Interview Questions for Parents Who Participated in Family Centered Rounds

1. **Participation**:
    a. How did the team prepare you for the FCR process? Did you know what time rounds would begin?
    b. Did you know everyone on the team and their roles or job?
    c. Were your questions answered in ways that you understood?
    d. Thinking back, would you have preferred a 1:1 update with anyone instead of the entire team process? Who, and why?
    e. How did family-centered rounds help you be part of decisions for your child's care?
2. **Information Sharing**
    a. How did the rounding team communicate with you and share information about your child's
        i. plan for the day
        ii. Medications and/or Pain management (if applicable)
        iii. Transition or discharge planning
    b. How did the rounding team include you and seek any information or input from you about your child and his/her care?
    c. Were there any questions or concerns that were not addressed? Could you describe those issues?
3. **Respect & Dignity**:
    a. How did the team show respect for your (parents /caregivers') experience with your child, knowledge of your child's condition & procedures?
    b. How were your and/or your child's emotional needs supported and addressed during FCR?

Additional questions:

4. Structure of team: Do you think the right people were on the FCR team today?, i.e. were the best disciplines or departments there based on your child's needs?
    a. If not, who else would you have liked to see on the rounding team?
5. What was the most helpful part of FCR for you as the parent?
6. Was there anything difficult or challenging for you during the FCR?
7. Is there anything that the team could have done differently to make the FCR a better experience?
8. How do the daily rounds affect your experience here at the hospital?
9. Any additional comments about your experience with FCR?

Chapter 5

SUMMARY AND IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

These studies demonstrate the value of Family Centered Rounds (FCR) as part of a pediatric hospital experience. FCR support concepts of patient- and family-centered care (PFCC), especially participation, information sharing, and dignity and respect. FCR provided various advantages to parents, patients and providers. Benefits included enhanced information exchange, communication, as well as possible administrative efficiencies. Parents' and patients' participation in rounds helps ensure that parents and/or patients contribute to shared decision-making about care. FCR provide a medium for parents to share their perspectives and concerns with the team of healthcare providers, thus contributing to aspects of dignity and respect along with information sharing.

FCR, as practiced in this setting, reflect a culture that values parent or family participation and also comprises frequent information exchange between parents and healthcare providers. Updating parents about their child's current status and daily plans was almost universal in FCR in this setting. Furthermore, FCR provided ample opportunities for parents to ask questions and receive answers, thus contributing to information sharing while supporting parents in their own knowledge and care of their children. In addition, when multiple healthcare providers participated in FCR, parents perceived better communication, information exchange and coordination of care between multiple providers. However, inconsistent communication between subspecialists and with parents may be problematic due to mixed messages or delays in communication that negatively impact information sharing with parents; in addition, possible delays in interventions may occur due to delayed communication between providers.

Parents generally viewed FCR as a very positive experience, especially because of the information they received from the healthcare providers. FCR facilitated dignity and respect by considering parents' experience with their children and including parents' input and values for decision-making. Overall parents perceived communication to be effective during FCR especially when providers

used lay language; alternatively, parents with professional knowledge or more experience with their child's condition were more likely to understand and to possibly request more medical terminology and information. Information, communication, and respect are elements of the patient experience that are reported on the Hospital Consumers Assessment of Healthcare Providers and Systems (HCAHPS®). Thus, efforts to improve FCR and other activities that support these elements could potentially result in higher scores on the HCAHPS® for those questions related to patient or family experience.

Despite the benefits of FCR, this research also demonstrated aspects of FCR that are inconsistently practiced and may need improvement. Nurses were highlighted as a valuable team member in FCR for the purpose of supporting families as well as facilitating better coordination of overall care. Nurse presence in FCR at this hospital was indeed higher than reported in the literature, however, upon closer review of observations and parent input, nurse presence in FCR was not always the child's primary bedside nurse, and nurse presence was challenged by other factors. This discrepancy highlights potential structural and process barriers in the practice of FCR. Staffing models, alternative models of nursing-led rounds, or change in medical team behavior may help alleviate some of these barriers and increase the bedside nurses' participation in FCR, thus achieving even better care coordination and communication between all healthcare providers involved in a child's care.

Healthcare providers' behaviors varied with regards to the FCR checklist activities but also non-verbal communication and interactions with parents and families. A FCR checklist may provide more standardized processes during FCR, and healthcare providers may also benefit from additional role modeling and/or education about FCR and specific strategies or techniques to enhance communication and interactions with parents and patients. Hospitals that stressed effective communication and clinician-patient interactions were found to have higher scores on the HCAHPS® (Aboumatar et al., 2015). Thus, any efforts to improve or enhance healthcare provider behavior with verbal and non-verbal

communication and interaction with patients and parents may improve the overall patient or family experience.

Processes of orientating parents and families to FCR would also improve the practice of FCR in this setting. Because parents appreciate being included in FCR, they may be more prepared and available to contribute important and relevant information if they understand the purpose and schedules of FCR. In addition, better orientation to FCR would also demonstrate respect for parents' personal dignity by providing them with opportunities to be awake and to manage their own self-care and activities of daily living, e.g. getting dressed, showering, and breakfast, etc. Being fully awake and alert for FCR may also allow for more effective cognitive processing of information by parents, thus possibly contributing to better parent education and preparation for safely caring for children during the hospital stay as well as after discharge.

Recommendations for improving the practice of FCR based on this research are as follows:

1. Increase the education and training for medical trainees, e.g. residents and/or medical students, re: FCR. Currently, residents are provided with one presentation during orientation (J. Serwint, personal communication, 6/26/2017), after which these concepts are to be reinforced by senior residents and attending physicians during daily FCR. Residents and medical students may benefit from engaging in simulations and role playing of FCR to enhance their communication skills and skills in facilitating FCR. In addition, more frequent participation in FCR by attending physicians would allow for real-time teaching and feedback along with integration and application of feedback. This was evident during FCR when attending physicians provided suggestions and examples to residents and medical students. Note, since this study commenced, this hospital has developed new strategies of assigning hospitalists to patient care, thus an attending physician should be participating in all FCR in the future and can facilitate better application of patient- and family- centered concepts during FCR.

2. Consider using a FCR checklist to standardize the process and facilitate more frequent completion of FCR activities. The FCR observation form used in this study corresponds to a FCR checklist and toolkit that is freely available at https://www.hipxchange.org/FamilyRounds. The toolkit also includes additional training materials to facilitate effective FCR. Alternatively, the hospital could develop its own FCR checklist that is customized to reflect valuable FCR activities in this setting. Cox et al. (2017) demonstrated that utilization of the FCR checklist improved the process of delivering FCR, which enhanced quality of care.
3. Conduct sporadic audits and walk-arounds for real-time observations and feedback. Spontaneous observations of FCR would allow for immediate feedback to healthcare providers regarding strengths as well as suggestions for improvement in FCR actions. Observations would also allow leadership to understand the facilitators and barriers to effective FCR. As reported by Aboumatar et al. (2015), leadership rounds with patients and staff provided opportunities to identify areas of concerns that directly impact various elements of patient care. This may not only support healthcare providers in the practice of FCR activities but also help facilitate awareness of and improvement in non-FCR activities.
4. Explore resources and strategies to support bedside nurses' participation in FCR. This may require an examination of resources, e.g. nurse to patient ratios, or a model of FCR that utilizes nursing-led rounds. Such a model may or may not be feasible based on a myriad of complex factors surrounding FCR including schedules of multiple teams and staff members.
5. Increase communication between subspecialists for children with complex conditions. Coordination of care, particularly for children who receive care from multiple specialists, is crucial to providing good quality of care but also to help ensure a better overall hospital experience. While collaborative rounds may not always be practical, efforts must be made for

multiple providers to communicate more effectively with each other and with parents, and thus to also increase consistent information sharing with parents.

6. Consider evening and weekend formats of FCR. More timely updates and information sharing is consistent with an element of quality of care from the Institute of Medicine's report (2001). Evenings provide additional opportunities for families and patients to participate in the exchange of information, especially in an acute care facility when changes in a patient's status or treatment plan may occur more frequently than is communicated in the current once-daily FCR. Weekends also present important times to ensure adequate communication between providers and with families and to ensure continuity of care. In addition, evenings and weekends may also facilitate participation by more parents, particularly those who are not available during the weekdays due to work responsibilities or other family obligations, e.g. caring for other children at home.
7. Provide more information and better orientation to FCR for parents. Because parent participation is valued, parents should know more about FCR as well as their role in FCR and their options for participation. Having an approximate time schedule would allow parents to plan their personal self-care or to arrange their travel plans if commuting to the hospital. In addition to providing information about FCR to parents, signs could be posted on patients' doors that would indicate the parents' or patients' preference to participate in FCR and also if they wanted to be awakened for FCR. Similar signs were posted on only two patients' doors during this study period, but such signs alerted the healthcare team to the parents' preference while also signaling whether the team should awaken the parents or patient, a dilemma that was observed in several FCR encounters. Posting signs on patients' doors is consistent with the practice of FCR as described at the Cincinnati Children's Hospital (n.d.); parents are oriented to rounds at admission and their preference for participation in FCR is marked on a card and

posted on the door. A sign on the door may also prompt parents to ask about FCR if orientation was not provided.

8. Increase engagement of patients, especially adolescents. As noted in the observations of FCR, adolescents were often not invited to participate in rounds, especially if they were asleep and parents were not available in the room. Adolescents need to develop more autonomy and responsibility for their own health, thus participation in rounds may facilitate information sharing while respecting their values and input. Patients' preferences for participating in FCR and being awakened for FCR could be noted on a card and posted on their door, as noted above.

The above recommendations relate to the practice of FCR in this hospital setting but may be applied in other settings, if appropriate. Further research on FCR is recommended to determine the impact of FCR on quality of care and the patient or family experience. More specifically, research could be conducted to explore any possible efficiencies with residents' and physicians' workloads related to FCR and caseload management. In addition, studying strategies to increase effective communication and collaboration among multiple providers would be helpful to improve coordination of care. Few studies have been conducted that examined administrative outcomes, thus future research could examine the association of FCR with length of stay, resource use, readmissions, and safety. Patient experience scores on the pediatric HCAHPS® may be useful as a means of monitoring specific elements that are related to FCR. Although the current study obtained narrative feedback from parents regarding their experience with FCR, additional feedback from parents and patients should be gathered as an ongoing means to monitor FCR and make changes, if warranted, to improve parents' and patients' experiences. FCR could be examined for outcomes of patient outcomes or parent and patient knowledge about healthcare conditions and care, especially after discharge, which is a critical point of transition. Finally, research on FCR in children's and adolescents' behavioral health or psychiatric settings is warranted because no literature was found during this research study. Concepts of patient- and family-

centered care are equally important in psychiatric settings, and FCR may help support parents' knowledge and care for their children with psychiatric conditions.

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Biographical Statement:

Deborah Waltermire-Burton is a native of Verona, NY and grew up in Pittsburgh, PA. She earned a B.S. degree in occupational therapy (OT) from Elizabethtown College in January 1989 and worked for the State of Maryland and then the Sheppard Pratt Health System, providing clinical services to adults with various psychiatric conditions, most notably schizophrenia and psychotic disorders. She was an active clinical fieldwork educator for many OT students during her clinical practice. Debbie earned a Master of Health Science degree in Health Finance and Management from the Johns Hopkins School of Hygiene and Public Health in 1995 and proceeded to work in an entry-level management role in the rehabilitation department at Sinai Hospital, Baltimore MD. In 1997 Debbie began her academic career as the OT Fieldwork Coordinator at Elizabethtown College, and she transitioned into a lecturer role in 2005. She has taught courses in OT Administration and Management, Psychosocial Interventions, Group Process, and Research II. Debbie has supervised numerous undergraduate and masters-level OT students' research projects and has presented many of these at state and national OT conferences. Since 2009, Debbie has served as an active member of the Pediatric Family Advisory Council at the Johns Hopkins Children's Center and has contributed to various initiatives that represent patients' and families' perspectives on hospital policy and practice. In addition to patient- and family-centered care, Debbie's research interests include sensory processing in adults with schizophrenia, and occupational engagement and participation in social or physical activities for children with congenital heart defects.